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Introduction

This investigation has two aims. The first is to identify risk factors associated with loss of neurogenic bladder and bowel which may increase medical and psychosocial complications after SCI. The second aim is to determine the influence of bladder and bowel management, complications and psychosocial and behavioral factors on quality of life (QOL). These aims will compare results of veterans with SCI with non-veterans with SCI. A mixed method approach has been used for data collection and analysis. Qualitative individual interviews have been conducted with two groups of participants: persons with SCI (target N=40) and caregivers (target N=20). Interviews are supplemented by quantitative measures to assess methods of managing neurogenic bowel and bladder after, associated medical complications and the impact of these in QOL. Data collection is complete at both research sites (The Ann Arbor VA and the University of Michigan Health Systems), including focus groups. A total of 60 audio files have been transcribed and checked for accuracy. Coding is completed on all individual interviews with the focus groups coding not yet completed. Data analysis is on-going and is currently focusing on an in-depth analysis of the nature and prevalence of SCI-related complications and their neurogenic bowel and bladder management; the identification of common themes across participants' transcripts, and qualitative and quantitative data comparisons based on military versus civilian status, age, neurological classification and time since injury. Results from quantitative data analyses so far show no significant differences between veterans and non-veterans with SCI in terms of QOL outcomes. Other preliminary results are described later in this report. One presentation on the preliminary data was given at the International Society of Physical Medicine and Rehabilitation 2015 meeting by the PI. Further deliverables included an extensive data analysis matrix of medical complications associated with neurogenic bladder and bowel and quality of life, and one published article on women with spinal cord injury and neurogenic bladder and bowel by this team of researchers and led by then post-doctoral fellow, Andrea Nevedal, currently at the Palo Alto VA.

Body

The body of this report is a narrative serving to outline the tasks and work performed during the third year of the project. It is divided into six sections, as per our approved Statement of Work. This report is focused on Year 3 (Months 25 to 36), between 10/01/14 and 09/30/15. Relevant materials from Year 1 and Year 2 are retained for clarity.

1. Administrative tasks

Tasks include those being performed at the different sites as well as project start-up and recruitment of personnel; coordination with work sites; re-submission of IRBs; meeting with advisory committee members; maintaining relationships with Department of Defense CDMRP and SCI program representatives, PM&R grant administration budget reviews; coordinating and overseeing consultants' involvement across sites. Three sites are involved: 1) University of Michigan/Dept. of Physical Medicine and Rehabilitation (lead site/PI: Tate); 2) VA Ann Arbor Healthcare System (site PI: DiPonio); and Michigan Paralyzed Veterans of America (site contact: Michael Harris). This third site serves exclusively in the function of recruitment, dissemination and guidance to project activities. Mr. Michael F Harris, Executive Director of MPVA has agreed to serve on the Steering Committee or Advisory Board for this project. Data collection was conducted at the first two sites listed. The final individual interviews were completed in Month 32. Focus groups were completed by Month 34.

1a. Project start-up activities (Months 1-6)

Start-up activities were conducted successfully during Year 1 and were reported in Year 1 annual report. Additional activities relevant to this category that were continued or completed during Year 2 were reported in Year 2 annual report.

A review of our accomplishments in Year 2 and of the proposed timelines was conducted in Month 25 to plan for Year 3 activities. The project PI and the Study Coordinator met weekly to discuss process and further plan new activities. Two main tasks were addressed: planning/carrying out focus groups and designing/carrying out data analysis plans for multiple publications and presentations.

1b. IRB and other regulatory approvals required by UM, VA and CDMRP (Months 2-6)

The IRBs for both sites were prepared, submitted and approved during Year 1. Continuing reviews were submitted and approved in Year 1 and Year 2 for both data collection sites. Continuing reviews for both sites were prepared, submitted and approved for Year 3 (UM Month 35; VA Month 26). Continuing review deadline for the VA for Year 4 is approaching and will be completed in Month 39 (into the approved no-cost extension period).

1c. Submission of research reports to the Department of Defense (Months 11, 24 and 36)

All quarterly reports for Year 3 were submitted as required, on or before 15 January 2015, 15 April 2015, and 15 July 2015. As instructed, the present annual report stands as the research report meeting quarterly report requirements for October 2015.

1d. Consultants agreements/scopes of work and timelines confirmed (Months 1-3)

This activity was successfully conducted during Year 1.

1e. Establishment of DSMB (Data Sharing and Management Board) (Months 3-6)

This project is not a clinical trial or intervention study and does not require a DSMB.

1f. Contract with transcription services (Months 3-4)

Data transcription services were secured for the UM arm of the study through a private company (Datagain) with UM IRB consent, signed non-disclosure agreements, and a payment system established through the PM&R grant administration office. All transcripts from the UM side of the study are complete. Datagain also provided transcription services on the three focus groups conducted during the study. Our business with Datagain is at an end. The VA transcriptionist services were set up by hiring a private temporary employee who was already approved to work at the VA. All transcripts from the VA side of the study are complete. Ms. Sarah Steffens was also enlisted to deidentify and correct errors in the focus group transcripts, which she has completed. Ms. Steffens' temporary assignment ended as of 30 September 2015.

1g. Payment for subject fees for participation (Months 6-30)

Subject fees have been paid as participants complete data collection activities, beginning in Year 1 and continuing through the end of data collection in Month 34. This includes all individual interviews and focus group participants.

Addendum 1a. Update on research assistant staff

Roxanne Madrid, MA and Sarah Steffens, BA have both departed the study following their important contributions. Ms. Madrid was instrumental in our coding and data analysis during Year 3. She will remain involved with publications given her availability, interest, and applicability of her skillset. Ms. Steffens contributed her talents in transcription, making our data analysis possible. Emily Zafiroff, BA is still with the project and continues to be instrumental in coding and data analysis. Ms. Zafiroff will continue with the study as we finish coding and preparing manuscripts for publication.

2. Research Design

Tasks include refinement of the new coding schema for SCI participants, discussion of steps required for both the qualitative and quantitative aspects of the study; establishment of a database for quantitative data collected; and systematic review of the literature (Months 1-10)

2a. Development, refinement and review of interviews and study measures (Months 1-3)

This activity was successfully conducted during Year1.

2b. Pilot of measures and interviews with SCI participants and caregivers (Months 3-4)

This activity was successfully conducted during Year1.

2c. Refinement of Bladder and Bowel Diary format and reporting forms (Months 3-5)

This activity was dropped as it was felt that it would duplicate work being done already by the UM SCI Model System program. This was discussed in a letter to the sponsor addressing reviewers concerns to avoid duplication of efforts between this newly funded project and the UM SCI Model System project funded by National Institute on Disability and Rehabilitation Research.

2d. Development of databases in word, Excel, SPSS, and NVivo (Months 5-10)

This activity was successfully conducted during Year 1. Databases have been instrumental in the tracking and storage of data, implementation of our coding procedures, and data analysis.

2e. Review of plans for data sharing and dissemination of products (Months 7-10)

Because the project start date was delayed due to VA IRB issues this activity was not completed during the first year. These were addressed during Year 2. See relevant “dissemination” and “reportable outcomes” sections below for more discussion.

Addendum 2a. Refinement and review of the project coding scheme (Months 15-18)

This step was taken in Year 2 and been implemented throughout Years 2 and 3. The coding scheme has been instrumental in managing our large dataset. We have been implementing additional coding as needed for more nuanced data analysis.

Addendum 2b. Development of matrices for qualitative data analysis (Months 27-36)

Over the course of the last year we have developed and implemented a process by which we generate topic-specific matrices of qualitative data towards the production of publications and conference presentations. These will also be instrumental in the development of the final report for this grant. Details outlined below under Data analysis and evaluation tasks.

3. Recruitment related tasks

Tasks include development of a plan for recruitment to include all sites with special attention given to the VA and MPVA. The U-M SCIMS database will serve as another source of recruitment as will our SCI Registry and community-based agencies. (Months 5-30)

3a. Send letters of invitation, phone contacts, informed consents and conduct eligibility verification with participants; scheduling interviews and focus groups (Months 6-25)

This activity was successfully begun during Year 1, continued through Year 2, and completed in Year 3. Use of recruitment databases, advertising through approved flyers, and referrals from physicians and advisory council members greatly assisted in our recruitment. Recruitment for focus groups came, as described in the original research protocol, from those who had participated in our individual interviews.

3b. Organize interview schedules and focus group activities with the sites (Months 6-25)

Interviews were scheduled between the participant and staff member(s) assigned to interview them. This process worked well and allows the staff and participants flexibility in

making and keeping appointments. All interviews (N=60) were completed by Month 32. Again, this delay was due to the delayed start of the entire project and overcoming some recruitment difficulties. Further, Focus groups (N=2) were planned, scheduled and successfully conducted during Months 33 and 34.

4. Data collection and data processing tasks

Tasks include conducting interviews/focus groups with the 80 participants (persons with SCI and caregivers); conducting focus groups; processing qualitative and quantitative data and data entry (Months 6-33). All 60 individual interviews have been conducted. Two focus groups were conducted involving a total of 18 participants.

4a. Train interviewers, conduct individual interviews, administer measures (Months 6-30)

Training was conducted in Year 1. Interviewing and administering measures was completed in Month 32.

4b. Have SCI participants complete 2-week Bowel and Bladder Diaries and Summaries (Months 6-31).

This activity was dropped as it was felt that it would duplicate work being done already by the UM SCI Model System program. This was discussed in a letter to the sponsor addressing reviewers concerns.

4c. Enter data based on subject diaries into SPSS database (Months 7-32)

N.A., see information above.

4c. Conduct two focus group interviews, with SCI and caregiver groups (Months 25-30)

Focus groups were conducted in Months 33 and 34. The first focus group was for those with SCI and involved 12 individuals. This group was deemed too large for effective communication and to provide ample time for all participants to convey their thoughts. As a result, the group was split into two smaller sessions. Each session consisted of six participants. Group 1 was moderated by Study Coordinator Rohn with the assistance of Consultant Roller. Group 2 was moderated by PI Tate with the assistance of Research Assistant Madrid. Both focus groups used the same question protocol and lasted approximately 2 hours.

The SCI groups were well attended, with 12 participants enjoying a luncheon before dividing into two equal-sized groups for the event itself. It was a challenge to divide the groups in such a way as to be representative of the entire sample, while also taking personalities and other issues into account. In the end, we built two well-rounded groups that captured the diversity in our larger sample. Group 1 consisted of four men and two women, ranging in age from 35 to 63. Time since injury ranged from 1-2 years to 37 years. Two of the participants were newly injured. Three of the long-termed injured were veterans. About half had caregiving services of some form. The levels of injury were a range, including 2 complete paraplegia, 2 incomplete paraplegia, and 2 incomplete tetraplegia. In general, the group discussion was very dynamic though at times some of the participants needed to be drawn out, and eventually everyone participated. Topics ranged from some concise definitions of quality of life, to issues around caregiving, to general concerns about bladder and bowel management.

Group 2 consisted of six men, ranging in age from 42 to 61. Time since injury ranged from 1-2 years to 36 years. Three of the participants were newly injured. One of the newly-injured

persons and three of the longer-term injured persons were veterans. Two of the four had some form of caregiving services. The levels of injury also were broad, including 3 complete paraplegia, 2 incomplete paraplegia, and 1 complete tetraplegia. In general, this group was also very dynamic and at times resembled a support group, with those injured some time ago providing advice to those newly injured. While specific conceptualizations of quality of life were not as well explored, the group did highlight problems and struggles with sexuality, the sense of manhood, managing and coping with bowel and bladder issues, and provided a lot of advice sharing among the group. Several group participants expressed strong negative emotions about their personal the struggles with disability (especially during the initial years) and their current quality of life. An interesting dynamic emerged wherein those who were incomplete seemed to feel less “permitted” to complain about their experiences, and a couple of the other participants immediately correcting them, assuring them that, in a sense, their less-visible injuries means they may actually have a harder time being understood by others. The group also commented at length about resiliency gained from military service, coping with anger and depression after first being injured, and dealing with insurance companies.

A second focus group session was planned for caregivers of those with SCI and involved 6 caregivers. Ms. Roller played a critical role is assisting researchers with the organization of this focus group session. This group size was ample for good communication and interactions, with considerable time for each participant to voice their views. This group was co-moderated by Study Coordinator Rohn and PI Tate. The question protocol used was based on the one used for the SCI participants but modified to reflect caregiver-specific circumstances and concerns. The group consisted of 5 family member caregivers and 1 non-family, agency caregiver. All provided services for participants in the SCI arm of the study. Topics ranged from what activities the caregivers provided for their family member/client to the emotional impact of the work they do. Social and economic concerns were also prevalent, including interruptions to expected life trajectories of retirement, financial security, and interfacing with insurance companies. Shared reflections and stories helped us to understand commonalities across the caregiving experience. Sexuality and intimacy were candidly discussed as well, assisting us in understanding the life experiences of those spouses whose sexual relationships have changed. Finally, the family roles each caregiver played, including even the agency caregiver, were characterized as important to the wellbeing of the person with SCI.

All focus group sessions have been transcribed and we have begun considering the best approach to begin coding and analyzing this data.

4d. Mail audio files to the transcription services (Months 9-31)

All audio files for individual interviews have been transcribed. All completed transcripts have been checked for accuracy and cleaned of all remaining identifying information on an on-going basis. The final transcript was received in Month 34. All transcripts have been loaded into NVivo 10 for coding.

4f. Have focus group audio files transcribed, enter narratives into NVivo database and code interviews (Months 22-33)

Focus group audio files were transcribed. All completed transcripts were checked for accuracy and cleaned of all remaining identifying information. The final focus group transcript was completed to this stage in Month 36.

The last of the coding for the individual interviews was completed in Month 36. This coding scheme was subject to careful inter-rater reliability checks. Coding for focus group transcripts has not yet begun. The research team will meet in the coming months to discuss coding procedures for these lengthier, more-complex, multi-subject sessions. The application of

the relevant existing coding scheme (SCI or caregiver) to the focus group sessions will be assessed and a determination made for any modifications to be made to reflect the group dynamic.

5. Data analysis and evaluation tasks

Tasks include mixed method analysis and triangulation of data. Includes evaluation of activities related to the conduct of the investigation itself (Months 11-35).

5a. Prepare basic statistics to describe samples and their scores; perform statistical analysis and qualitative analysis of transcripts for themes and patterns (Months 11-34)

Four significant qualitative data analysis procedures have been implemented, each designed to result in a presentation and/or publication that will also allow us to begin addressing the aims of the larger project. They are as follows:

1. **Bladder and Bowel Complications:** We conducted a systematic review of the interview data, guiding by our NVivo coding, to create a free list of all cited complications and generated frequencies across the SCI sample (N=40). From this task Rohn and Zafiroff surveyed all 40 interviews separately in order to test for inter-rater reliability and be assured of accurately capturing all the cited complications. Urinary track infections (UTIs), bladder incontinence, hemorrhoids, and bowel incontinence were identified as the four most frequently cited and medical complications. A matrix of participants' salient discussions of these complications has been prepared. Currently, further analysis on this project is on hold pending completion of the first two projects, including their attendant publications. We will be resuming work on this analysis in the coming months.
2. **Lower ratings on QOL:** A matrix reflecting quality of life quotes from participants reporting lower QOL ratings was prepared by Consultant Duggan in collaboration with the research team. The intent was to identify common themes among those with lower QOL (ratings of 7 or below). This work is on-going.
3. **Response Shift and QOL:** To capture the richness of psychological coping and adjustment issues reported by participants during these interviews, researchers chose to test a response shift theoretical framework (Schwartz et al.), which explains different components of adjustment and other factors leading to QOL appraisals. This analysis involved a complex process of evaluating all 40 participants in terms of their response shift mechanisms and current adaptations to SCI, bladder and bowel dysfunction, as these relate to their self-reported quality of life. The result was a comprehensive matrix that tracked direct responses in the form of salient quotes. From this matrix, themes were derived and patterns were recognized and explained using response shift theory and by correlating with quantitative analyses. These data will be orally presented on October 24th 2015 by the PI at the 2015 Annual Conference of the International Society for Quality of Life Research. An abstract has been published in the Journal of Quality of Life Research. Manuscript preparation will follow through 2015. Target journals include Disability and Rehabilitation and the Journal of Quality of Life Research.
4. **Resilience and Aging with SCI:** For a publication tentatively entitled "Resilience in Women Aging with Spinal Cord Injury and Neurogenic Bladder and Bowel" for

submission to *Disability & Rehabilitation*. This analysis mirrors the above analysis; however it focuses on the lived experiences and displays of longitudinal resilience for two study participants, who by chance had participated in a related study ten years ago. We are analyzing their responses as they relate to the resilience model put forward by Monden, et al (2014). Study Coordinator, Rohn, is taking the lead on this analysis and publication, with Tate, Zafiroff, Madrid, and Nevedal assisting.

From a quantitative analysis perspective, data was compared using ANOVAs, Chi-square tests and in some cases multiple regressions. Preliminary findings are as follows. The most common method of bowel management was digital stimulation, used by 65% of the all participants, followed by digital evacuation (47.5%), rectal suppositories (40%) and laxatives and/or other oral medications (37.5%). For bowel management, the most common method was intermittent catheterization by self, used by 57.55 of participants, followed by intermittent catheterization done by others (20%), suprapubic catheterization (7.5%), transurethral indwelling catheterization (7.5%), and normal voiding (7.5%). No differences in either methods of bowel or bladder management were observed as a function of military experience.

Those using laxatives and/or other oral medications for their bowel were less likely to experience bowel complications than were those who did not, 26.7% vs. 60.0% ($p<.05$). None of the participants who had colostomies reported having constipation compared to 50% of those using other methods. In terms of bladder complications, those who used Intermittent Catheterization independently were less likely to have experienced UTIs in the past year than did others, 43.5% vs. 88.2% ($p<.005$). These persons also were less likely to experience involuntary bladder leakage, 21.7% vs. 35.3% of others ($p<.05$). Conversely, of those who used Intermittent Catheterization but had this done by another person more were more likely to have UTIs 100% vs. 53.1% of others ($p<.05$). There were no differences in bowel complications as a function of military experience. Those who served in the military were less likely to experience UTIs, 50.0% vs. 77.8% though this difference was not statistically significant ($p=.07$). No differences in satisfaction were observed as a function of military experience. Response shift ratings were significantly associated with participants' QOL ratings ($p<.006$). There were significant differences in the PROMIS Global Physical Health and Depression scores as a function of response shift – those showing no changes or response shift had the lowest PROMIS scores.

5b. Conduct triangulation of qualitative and quantitative data sets (Months 15-34)

Triangulation between qualitative and quantitative data has been conducted in a focused way around the current qualitative data analysis projects. Qualitative findings on complications following neurogenic bladder and bowel (including hemorrhoids, constipation, incontinence and urinary tract infections) are being analyzed as compared to quantitative measures from our BBTI, PROMIS, and SCI-QOL measures. Thematic patterns and quantified response shift scores have been compared to self-reported QOL scores, SCI-QOL and PROMIS scores, and tested for correlations in age, sex, veteran status, and time since injury. Further, we propose comparing rates of complications to response shift and QOL scores, further exploring differences between veterans and non-veterans. Themes will be generated and tested against these quantitative measures, drawing correlations between those facing more or less complications and how veteran status impacts QOL. As analysis proceeds, more comparisons will be made, to further triangulate the available data to help contextualize and explain both qualitative and quantitative findings.

5c. Review data regularly to evaluate coding schemes, discuss patterns emerging, and findings from the quantitative analysis (Months 13-33)

Team members have already begun discussing patterns that seem to be emerging from the data set. Regular meetings between staff members and consultants continue to take place to maintain a unified sense of purpose moving forward. Dr. Duggan continues to play an important role in providing guidance to this process. MS. Roller has provided insightful input with respect to participants' responses to dealing with challenges associated with bowel and bladder.

Three large data analysis projects are underway (described below), which necessitated frequent meetings throughout the year. These meetings served to focus our analysis and approach consensus on the methods used to code and generate findings. To this end, our consultants (Duggan, Roller, Lequerica) have been invaluable assets in managing this complex dataset.

5d. Review focus group data and integrate it with other qualitative data (Months 20-33)

Focus group data analysis has not yet begun. The research team will be meeting in the coming months to discuss analysis and use of this portion of the dataset.

5e. Analyze data from the Bowel and Bladder Diaries, including conduct of linear mixed models (Months 24-34).

N.A. as detailed above.

5f. Conduct regular meetings to discuss data interpretation and evaluation (Months 11-35)

Members of the study team met on a routine basis (at least quarterly) for updates and to roll-out and discuss data analysis projects. These meetings have included reports on recent matrices and to identify themes and patterns in the processed data. Further, the PI and study coordinator meet weekly, alone or with research staff, to discuss progress on the data analysis and plan for publications and presentations.

6. Dissemination and data sharing tasks

Tasks include discussions with focus groups at U-M, VA and MPVA, presentations at the MPVA and national meetings, website links to project activities, products and findings. We will use the existing U-M SCIMS website with links to the VA and MPVA sites to distribute this information. (Months 10-36).

6a. Appointment of a DSMB and development of a data sharing plan (Months 5-10)

The project does not require a DSMB.

6b. Development and dissemination of findings in lay language to persons with SCI, their families and caregivers through a second presentation at the AACIL and MPVA, consumer brochures and fact sheets. These will be distributed through websites, presentations and meetings (Months 25-35).

As this is planned following the completion of data collection and analysis, this task has not yet begun. Relationships with the Ann Arbor Center for Independent Living (AACIL) and Michigan Paralyzed Veterans Administration are in place to schedule future presentations. As part of our recruitment efforts, Study Coordinator Rohn has met with and discussed initial

findings with potential participants at MPVA, during Year 1 and Year 2. An advisory council meeting is planned for later this year or next.

6c. Presentations at DoD and CDMRP sponsored meetings (Months 11-36)

NA – as these have not yet occurred. Invitations have not been issued.

6d. Preparation of final report and manuscripts (Months 15-36)

Final report will be prepared following the completion of the project. Project team members have begun writing manuscripts, to be completed as data are analyzed. Investigators, staff, consultants and collaborators discussed a number of potential additional manuscripts.

As reported above, three manuscripts are in various stages of preparation: one focused on complications from neurogenic bladder and bowel, one on response shift and quality of life, and one on resilience and aging. These three publications will be completed and submitted to their respective journals in the coming months.

One presentation was given during the reporting period, entitled “Response Shift and Perceptions of Quality of Life in Newly versus Long-term Injured Persons with Spinal Cord Injury”. This was presented at the International Society of Physical Medicine and Rehabilitation annual meeting. Conclusions: Notions of “independence” appear to change over time, reflecting a response shift as those living longer with SCI learn to adapt and redefine their independence as it relates to QOL. Recognizing these patterns can assist clinicians by signaling patient readiness to treatment that can best improve QOL. A number of other presentations were made by the PI on issues of neurogenic bowel and bladder following SCI included one invited presentation at the Canadian PM&R Society in May of 2015. These included two oral presentations at the American Spinal Injury Association, two at the International Collaborations in Repair Discoveries in Vancouver, Canada (invited) and one at the International Society of QOL in 2014. While these did not focus on the qualitative data from this project, they included qualitative quotes and quantitative data from a current larger study being conducted by the PI as part of the Spinal Cord Injury Model Systems project.

One publication went to press during this reporting period, entitled “Women’s experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel” published in Disability and Rehabilitation. Findings describe concerns, strategies, and the detrimental impact of neurogenic bladder and bowel in the lives of women with SCI. Gender-specific challenges suggest interventions for women with SCI are needed and can assist clinicians in treatment and improve QOL for their patients.

Key Research Accomplishments

- Completion of all data collection and transcription, including focus groups. Completion of coding for all individual interviews.
- Development of numerous important qualitative data analysis projects towards the preparation of three manuscripts.
- Completion of analysis for a presentation that was given based upon data analyses conducted throughout Year 3.
- Publication of one article in Disability and Rehabilitation regarding women's experiences with neurogenic bladder and bowel.

Reportable Outcomes

- All face-to-face interviews, focus groups, transcription, and coding were completed during this reporting period (see appendix for table reflecting this completion).
- Created an extensive data analysis matrix of participant responses, which allowed for the identification and description of four thematic patterns of response shift and quality of life, instrumental in preparing one of our manuscripts (see appendix for full text).
- Created a matrix reflecting quality of life quotes from participants reporting lower QOL ratings. Consultant Colette Duggan led these efforts in collaboration with the research team. This work is ongoing (see appendix for full text).
- One presentation given at an international conferences: the International Society of Physical Medicine and Rehabilitation (see appendix for abstract)
- One article was published in Year 3 focused on women with spinal cord injury and neurogenic bladder and bowel (see appendix for article):
 - Nevedal, Andrea, Anna L. Kratz, and Denise G. Tate. "Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel." *Disability and Rehabilitation* ahead-of-print (2015): 1-9.

Conclusion

We have completed all 60 interviews and the focus groups with both arms of the study population (SCI and Caregivers). We are grateful for the patience shown by the USAMRMC in providing a no-cost extension on our study. With the data collection and coding complete, and numerous data analysis projects and manuscripts well underway, we are confident that the coming year will be rich with important findings, manuscript preparation, and dissemination. Data on caregivers and focus groups have not yet begun, but will be included in upcoming analysis projects.

We have begun conducting both qualitative and quantitative analyses on the data, revealing some common themes as well as relationship trends among numerous factors. At this time, there are no apparent differences found between veteran and non-veteran participants in terms of how they responded to changes due to spinal cord injury. Time since injury is more significant impact on response to injury and neurogenic bladder and bowel. The veterans fell into the range of categories identified. However, the rates of these thematic patterns suggest that veterans clustered in some of the most extreme responses and quality of life ratings, often either completely responding to change and enacting active behavioral adaptations or having considerable difficulties and feeling “stuck”. We are continuing to test this finding. An in-depth analysis summary for the response shift-QOL project is provided in the appendix. Qualitative analysis on complications is ongoing and has not yet yielded reportable findings.

Quantitative analyses have begun to uncover some useful trends and correlations. For example, the range of complications was consistent across the groups, showing no significant differences between veterans and non-veterans. There were no differences in bowel complications as a function of military experience. Those who served in the military were less likely to experience UTIs, 50.0% vs. 77.8% though this difference was not statistically significant ($p=.07$). No differences in satisfaction were observed as a function of military experience. Regarding management, there were no differences in either methods of bowel or bladder management were observed as a function of military experience.

Supporting Data

Please find the following supporting data for Year 3:

1. SC11028 QuadChart
2. Table showing final tally of all completed interviews
3. Response Shift-Quality of Life Matrix
4. Response Shift-Quality of Life Thematic Analysis
5. Lower Quality of Life Quotes Matrix
6. Abstract from ISPMR presentation
7. Article published in Disability and Rehabilitation

PI: Denise Tate, PhD

Org: Regents of the University of Michigan

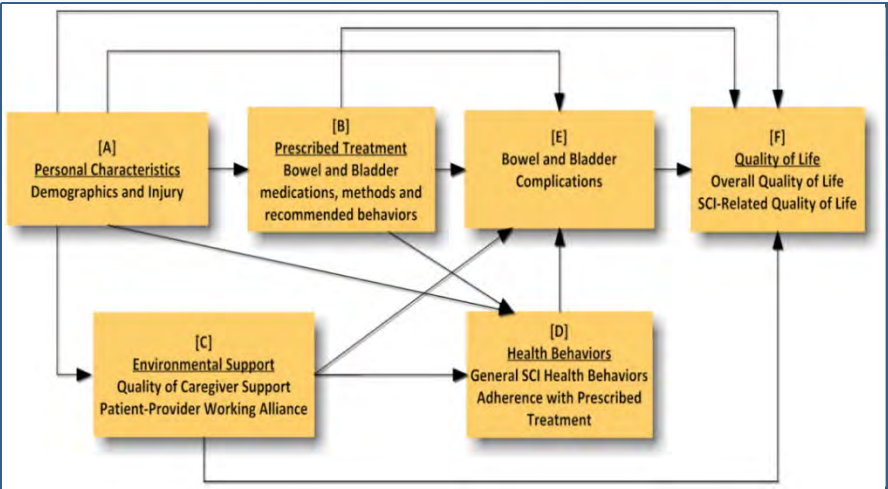
Award Amount: \$614,110

Study/Product Aim(s)

- To identify risks associated with neurogenic bladder and bowel complications after SCI.
- To determine the influence of these complications on quality of life.

Approach

The sample consists of 60 persons (40 subjects with SCI and 20 caregivers). The project uses a mixed method approach with both a qualitative and quantitative components. Issues around quality of life for those with neurogenic bladder and bowel are the key focus, as are differences between veteran and civilian participants. Data collection is complete and data analysis has begun, with multiple manuscripts in preparation stages.



Project has completed data collection. Coding and analysis is ongoing with an eye towards dissemination and first publications beginning in the first quarter of 2016.

Timeline and Cost

Activities	Project Year*	Y1	Y2	Y3
Administrative start-up (IRB, staff, equip)				
Research Design (surveys, databases)				
Recruitment (registry, flyers, referrals)				
Data collection and processing				
Data analysis				
Dissemination and data sharing				
Estimated Budget (\$K)		\$57K	\$215K	\$342K

*Y1: 10/1/12 – 9/30/13; Y2: 10/1/13 – 9/30/14; Y3: 10/1/14 – 9/30/15

Goals/Milestones:

Y01 Goals – Administrative start-up

- ☒ IRB and other regulatory approvals established and approved
- ☒ Staff hired and trained; consultant agreements finalized
- ☒ Equipment, data analysis software, and supplies acquired
- ☒ Research instruments and databases piloted, refined, and finalized

Y01-Y02 Goals – Data collection

- ☒ IRB-approved recruitment strategies formalized and implemented
- ☒ Data collection and processing begun and ongoing
- ☒ Completion of data collection and processing (transcription)

Y02-Y03 Goals – Data analysis and dissemination

- ☐ Apply statistical analysis and interview coding schemas
- ☐ Disseminate findings: funding agency, peer-reviewed journals, etc.

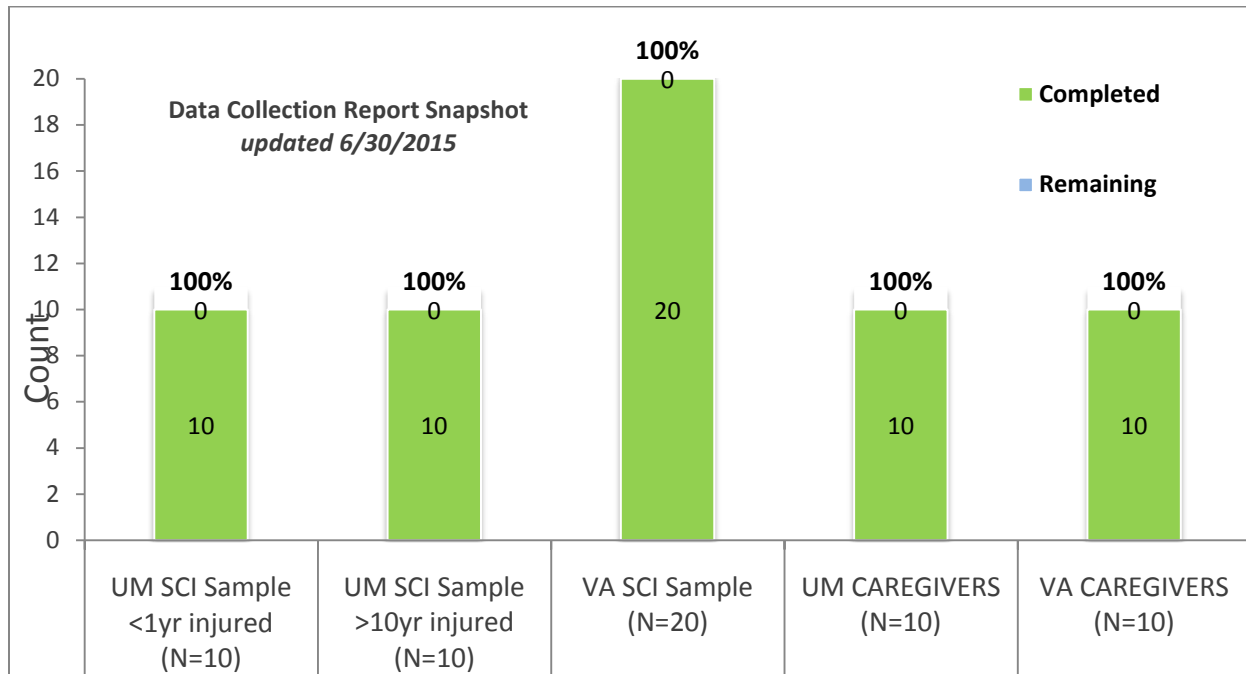
Comments/Challenges/Issues/Concerns

All data collection is complete. All transcription and coding is complete, with the exception of coding of the focus group transcripts. Analysis has begun on numerous projects. Data analysis is ongoing and publications are in preparation stage.

Budget Expenditure to Date

Projected Expenditure: \$467,956
Actual Expenditure: \$416,806

Table showing final tally of all completed interviews



Participant	Antecedents	Mechanisms	Response Shift	Perceived QoL
	Stable or dispositional characteristics of individual, including demographics, personality, expectations, and spiritual identity.	Behavioral, cognitive, and affective processes to accommodate the changes in health status (catalyst), e.g. coping strategies, social comparisons, seeking social support, reordering goals, reframing expectations and engaging in spiritual practices.	Defined as change in the meaning of one's self-evaluation of QOL as a result of <u>changes</u> in internal standards, values and the conceptualization of QOL. (Essentially, the result of antecedents and mechanisms responding to catalyst).	Multidimensional construct incorporating physical, psychological, and social functioning. (Essentially, patient reported QoL in summary, including overall happiness/lack of happiness, wellbeing, etc.)
UM-005 Female White 35/19ysi Vehicular Inc Para Auto NF No caregiver	Teacher, fulltime career, hobbies are writing, exercise; health focused; injured at 16. Was hit by a car in high school. SCI level – L2-L3 Response Shift: 1 Quality of Life: 7.5	I still see myself trying to recover even now. I don't think recovery ever really ends. I have a wheelchair and a walker but now can do a lot from crutches. I am afraid of falls. It is hard to walk with just a cane. It is hard when you are first injured to cath but my muscles are stronger now...	I think having SCI as a whole causes the insecurity for anyone... You don't feel as pretty, you don't feel as able, all of those things. But I've overcome those emotions... My strong point is that I don't stay in that place. I'm resilient... I attribute my healing to my faith and the Lord... I'm happy I can walk with crutches but I'm still not fulfilled.	Because I'm still not walking as good as I would like and because I still do have to catheterize, so for those two reasons. And the independence like you mentioned earlier, it's affected my social relationships. Like how independent I am feels great, but sometimes I do wish I did have more help.
UM-008 Female White 63/22ysi Fall Comp Para Private No caregiver	Married, worked as a commercial loan officer. Worked 21 years after her injury; co-workers very supportive. Currently retired. Owns a farm. Response Shift: 2+ Quality of Life: 7.5	...I know some people have a lot more problems than I do... Maybe I'm just fortunate I'm pretty healthy and I think the fact that I get exercise really helps to maintain my health... I just think all those things really help to maintain your health and allow you to deal with this better... I think that was important you've just sort of got to get back in the saddle and get on with your life.	...you have to get over being embarrassed about it I guess. It's just a fact of life everybody deals with... I mean you just have to sort of say look this is what I've got to do... you just mature with the whole thought of it all. It's just the way it is... Well I think you just have to come to terms with it... and realize this is the hand you've been dealt...	Well I'm, I was pretty successful in my career. You know financially I'm probably fine. I'm pretty comfortable I'm able to do some traveling and to be outside except in the winter. For the most part I've achieved a fair amount.
UM-009 Male White 50/28ysi Vehicular Comp Para Other No caregiver	Married. Student at UM at the time of his accident. Post-injury has been employed as a paralegal and makes custom jewelry. Response Shift: 3 Quality of Life: 8	And I suppose like anything else you just get used to things the longer they go on. You just kind of get used to having to deal with it... My wife would call that my pragmatism. She says I'm very pragmatic about everything. You know how do you do this, how do you get from A to B in the shortest amount of distance possible with the most efficient use of energy.	...it takes a little while to become accustomed to the fact that it's one more thing I have to worry about... Over time I guess I've found what my limitations are and I don't look at it as a struggle so much as just something I have to do... just notice the difference between a situation that I can have some input over and situation that have no input.. not waste my effort on things I don't have control over...	I mean I've got no real problems, you know, so I've really got nothing to complain about... Well, it's been like this for twenty-some years, so I don't waste a lot of time thinking about how things would be if it wasn't like this. This is what it is, so I guess I'm just looking at what I've got and I've got a lot.

UM-010 Male White 35/16ysi Violence Com Para Medicare No caregiver	Not married. Injured in attempted robbery. Prior drug addictions. Associate's degree in graphic and web design. Works freelance; free to pick his own schedule. Considers himself to be lazy. Response Shift: 1 Quality of Life: 6	I've pretty much gone through it all and I kind of know what to expect, you know, how to deal with different situations. But every now and then something comes up that's still surprising... And I'm still learning ways of dealing with it, you know what I mean? It still seems like each year I kind of get a little bit more understanding with how my body works...	And that's one thing I think the disability has matured me... I think if anything it's made me look at myself more realistically, you know... if I try to look at myself through rose-colored glasses then yeah, I get you know, totally like let down or something. So it makes me do a real honest evaluation of myself and what my capabilities are...	I'm not hopeless. I still see a lot of people and I'm like "I'm glad I'm not that guy or that girl," you know? I'm not stuck... I still, I've got options of what I can do with my life. And I'm still fairly healthy. I can think for myself; I can you know, I'm still fairly independent. I've still got good friends, good family; still got opportunity to make things better and do things I still want to do... I'm fairly comfortable with myself.
UM-012 Male White 56/12ysi Vehicular Comp Tetra Auto NF Caregiver	His wife is his paid caregiver. Has other paid aids. Strong family support that helps him maintain his home. He has reframed his career as a manager into family leadership/parenting role. Response Shift: 2 Quality of Life: 5.5	...it's actually allowed me to spend more time, when my boys were younger when I was first hurt, with my wife working a full time job...I'd actually spend time with the boys, teaching them how to cook dinners, to become more responsible than probably a lot of young people at their age... I'm happy to say that now I've got two young men that are self-sufficient independent.	That's probably my normal...that's who I am. I've always exercised prior to the accident... I think just that make up made a difference but at the same time I also knew when I got hurt that I needed to be able to have the strength to do things with my family... so your job's going to be to take care of yourself and continue to be as strong as possible so that this way we are able, as a family, to be able to do things... That's been my driving force	...it's always a plan, it's a schedule. It actually is a day to day schedule that many individuals that are not disabled actually can take for granted... Because I can't do everything that I once did. I remember what it's like not to necessarily live on a schedule. Yeah, you had a schedule with work. You had to be there and things like that but overall if I wanted to jump in the car and run someplace I did. And now I don't do those things.
UM-013 Female Black 63/36ysi Vehicular Comp Tetra Other No caregiver	Single. Injured in a motor-vehicle accident. Self-reliant but wonders if she needs an assistant as she gets older. Self-reported as independent and very active in the community. Response Shift: 2+ Quality of Life: 9.5	...so either get someone to help me when I'm out or I can't be out for so many hours. So that's the thing that kind of changed the quality of life is just trying to adapt to that... I've always been a person to attack any situation... I make an adjustment or if there's nothing that you can do about it you've got to just let it go... I'm really thankful that I don't have the bowel problems because a friend of mine is really going through that... I think my faith, my positive attitude and my strong will. If I didn't have that I probably wouldn't be sitting here talking to you.	I don't want to sound cocky, but I do anything and everything that I want to do. I really do.... It's just a matter of knowing where I am and what I need to do... And so I just sort of got comfortable with the fact that these things are going to happen to me... I would say the secret would be accenting the positives and trying to take care of the negatives. Don't get so caught up in all of the problems, but be aware of them and try and find solutions. And then it's just being grateful and thankful.	Because I think there's always room for improvement, but I'm pretty satisfied. I live. I don't just exist day to day. I'm busy. I'm active in my community. I wake up every morning wanting to get the day started. I love what I do. I think that I make a difference in my community and other people's lives. So those kinds of things help me to feel better about myself and it makes me think that I'm living a good life, so that's it.
UM-014	Married. Describes wife as devoted. C4-5 quadriplegic	I am active. I get out and do things. That's how I stay away from depression...	Don't get upset with it. Deal with it. It's who you are now. You have to... It's just	Self-rated Quality of Life: 9

Male White 64/41ysi Violence Comp Tetra Other Private Caregiver	injured by “horse play”. Employed prior to injury as a mechanic. Has 2 children, 4 grandchildren. Response Shift: 1 Quality of Life: 9	So I get out and go quite a lot. I don’t let the chair hold me back... Don’t leave things, you’re responsible for...Take care of your responsibilities. Don’t leave it in somebody else’s hands. It won’t happen.	like before. You have to get up out of bed every morning, have to do your morning routine. It’s just changed a little bit... Mind over matter worked for me. So mind over matter can do anything I believe.	My belief in God... If it could be better I’d be out of the wheelchair... Go do something fun, get over it. Go find something to occupy yourself some other way. Where the wheelchair limits me so much. I just can’t go do what I want to do... I was a very active person before and now I’m not.
UM-017 Male White 43/24ysi Sports Comp Tetra Self-pay Caregiver	Unmarried. Quadriplegic C 5-6, injured in diving accident. Has supportive parents and sister who act as his caregivers. Response Shift: 2 Quality of Life: 10	So I’ve always struggled. So being in that wheelchair was just a different struggle... So started realizing and understanding how much it does take. It is a job and I pay very close attention to it, and it’s the only way, if I didn’t I wouldn’t be happy. I would be sad. I wouldn’t be as happy if I didn’t pay the close attention.	I’ve learned a whole bunch. I really have, and I can really help others in this position.... you start looking through a different window. It’s not what it was... and we’re going to be in misery for a long time, move ahead. Did that happen? No. Took me two years. I beat my head off shit for two years. Didn’t happen overnight.	I’m very, very happy. I’m full of joy. I have everything that I could ever dream of before my accident, I have it right now. I have a beautiful girl that loves me. I have a home that’s beautiful. I have friends and loved ones that are there for me. It’s just so many good things in my life... Good things are happening.
UM-018 Male Hispanic 30/10ysi Sports Incom Tetra Medicare Caregiver	Married to someone he dated prior to injury but was not dating at the time of injury. C5-C6 injury. Finishing studies at Alma College Response Shift: 1 Quality of Life: 7	Yeah, it’s something my mom taught me to do, is to be my own advocate. And I kind of just followed her example while I was in the hospital. You know, I saw how she took care of business dealing with the system... so I try to adopt the fake it until you make it philosophy and that’s actually been quite successful or at least it gets me up and doing things.	I was just kind of taking it a day at a time during the summer before my injury. Once the injury happened it was like okay, I still have to take things a day at a time, but I’ve got fewer paths available to me to that bright shining future that all of us are striving for. Now I really don’t see any path to it at all, so I just kind of exist one day at a time.	It’s just shy of so-so okay, but it’s definitely not the worst it could be. You know I still live in the first world and that’s nice and I have first world problems... It happens when the things that I’m doing turn from interesting and fun to boring and repetitive, so there’s that.
UM-020 Female White 52/17ysi Vehicular Comp Tetra Other Caregiver	Married when injury occurred now divorced. Does not attribute end of marriage to SCI. PhD in Rehab Counseling. Response Shift: 3 Quality of Life: 9.5	...it’s a part of being human and that it didn’t kill you and maybe those kinds of things... In the beginning I would say that it had a pretty significant impact on me. It did. It was hard, it was embarrassing, it was a struggle... Just the drudgery of having to do it and some of the embarrassment of people knowing.	It’s all about adjustment... it’s not something that I’m at all embarrassed about or ashamed about. It’s just part of the process of having a spinal cord injury... I’m happy with my life. I’m not sitting in the chair waiting for the cure... I’m very, very resilient and I think that that’s what I can attribute to being where I’m at.	I’m totally empowered; I love what I do... I’ve achieved everything that I wanted to achieve in my life and more. I’ve actually exceeded my expectations of what I thought my life would be. And to be honest with you, had I not had the spinal cord injury I don’t know that I would be saying that.
UM-021 Female White	Retired police officer. Injured via abscess but is slowly regaining mobility and may	I marveled at the ones that would get up, get dressed and make it to work every morning over there at Shepherd’s... And I	Initially, it did, I guess, a lot more just because the bowel, especially. I was just...it was just so hard. Now, I can just	...is there some place or something else I could be doing to enhance my situation to make it better, to make me stronger, give

55/1ysi Medical Incomp Para Other priv Caregiver	still walk one day. Married; husband supportive. Response Shift: 1 Quality of Life: 9.5	could get moving a lot quicker than I do too. I just don't have to... I never did the "Oh, woes me," but I did think really, I said, "For me, as much as I like to walk and do things like that," and then I thought, "Well, would I have rather been blinded?"... you take what you can get.	get up and get going... My life's goal is to be happy and healthy and I am. So this is just different... I could have gotten shot and killed 20 years ago... things happen to everybody. We just kind of lived a charmed life and this happened and you have to deal with it.	me any other chances so I can be self-sufficient and stay that way a long time?... You just have to put yourself out there and go do it. My goals aren't changing really... My sense of self, I'm still very confident... And I've been lucky I've been able to learn to do it myself.
UM-023 Male White 57/1ysi Fall Incomp Para Medicaid No caregiver	Unmarried. 3 daughters. Has lived with his mother since his father died prior to the injury... he fell out of a tree-stand, T-12 injury. Response Shift: 1 Quality of Life: 5.5	Well, when you hear stuff like that, even though I was in bad shape at least I was walking... when you get severely injured if you don't want to die there's a lot of things you say to yourself you're going to have to do if you want to live. It just comes down to that plain and simple – if you want to live this is what you're going to have to do.	I never did [go out] even before my accident. I didn't go too many places... But if my bowels and my bladder don't straighten out and this is what I have to continue doing I'll do it. Like I say, there are certain things you're going to have to do different in your life than what you did before.	You look at some people that maybe have got it better than you and they've got this big old freaking mansion... But if you look on the other end of the spectrum there are probably some people that aren't as well off as what you are... You're always going to be able to find somebody that's better off than you are and people that are probably worse off than you are.
UM-030 Female White 45/1ysi Fall Incomp Para Medicaid Caregiver	Married, NH. Injury occurred at home with a fall down the stairs, breaking C6 to C7 and T1 has been damaged. HIV Positive. Response Shift: 1 Quality of Life: 5	I think that kind of made me feel like "Oh my God, why did this happen to me?"... but there was people that was worse off than me... Okay, I should be just thankful that I'm here and I can move more parts of my body than my legs... it's like being a baby all over again, learning how... As an adult you have to learn it all over again.	Me, I just look at it as part of the spinal cord injury and it's just something I have to deal with and figure out what I can do to fix it...so I feel like I've been given that second chance. I do. And somebody's told me I need to change a little bit or something. It's hit me hard. But I'm going to do what I can do, and I'm happy.	Like in the middle. I'm all right. I'm happy with it, but I want more. I wanted to -- I want it to be more happy... Being able to get out more and go see people, get my mind off of things. Being able to go out and watch birds, watch nature stuff. Just because I'm in a wheelchair doesn't mean I can't still do those things.
UM-038 Female White 36/1ysi Vehicular Comp Para Auto NF Caregiver	Fiancé caregiver, together prior to injury. T7 injury, has use of hands and arms. Has bowel sensation. Response Shift: 1 Quality of Life: 5	You have to rely on somebody to get you, you have to take pills to go poop... Well like I said I do what I can do and if I can't do it I figure a way out to do it... It's very hard for my family that I guess, that's something that should be addressed with the patient.	Basically I'm starting over... You know just because I'm paralyzed there just a new way of doing things. If I had my legs I wouldn't have this problem. The doctors need to work on some stuff and give me my legs back... I dealt with my injury and it had to be done so I deal with it.	Because it's not bad and it's not good. You make it out to what it is... Walking, being able to drive, ride a bike, doing things I used to do. So that's where I have to rely on people to take care of me. I don't like that... Just getting used to the lifestyle... Well my dream got taken away and my husband's did, all of them.
UM-039 Male White 42/1ysi	Mountain bike accident. College football. Military for 5 years. Divorced. Obese but trying to lose weight. Has a 7 year old son motivating him.	I immediately went into prayer mode... Please wash my sins away because I don't want to hell... It's been a long road though. It plays on you emotionally and mentally when you can't control your	I went for 41 years thinking I was invincible then all of a sudden very humbling... It definitely changed who I am... I don't judge people too quickly because I don't look the same... During the	Well, because before I got hurt I would probably have rated myself at eight...You know, just because I still wasn't as physically fit as I could have been, you know. So, you know, I'd say a six because

Sports Incomp Para Other priv No caregiver VETERAN	Can walk. Response Shift: 1 Quality of Life: 6	bowel... I felt less of a man... But it got a lot better... I went through some rigorous training. Just some mental toughness... that's the whole military style	first few months of my injury, you know, depression, I was eating garbage... now I am at least eating well... I learned how to live with it...	I'm more than half better than when I first started, when I first got home from the hospital, you know, so, if it's more than half, I'm going to have to say about 60%.
UM-040 Male White 61/1ysi Fall Comp Para Other Priv Caregiver	Married, adult children. Engineer for car seats. Currently has short-term disability. Injured less than 6 mos. Has some feelings in legs. Resides at rehab facility Response Shift: 1 Quality of Life: 7	...you can sit and feel sorry for yourself and dwell on it or you can take it day-by-day that you're waking up and you know you're here... I get up every morning and just thank God that I got another day... little things that I have to deal with aren't that big when you look at some other people... I could have been killed pretty easy so I'm just thankful to be here...	...it hasn't beat me up at all; hasn't changed me a bit. My nurses come in and they deal with it every day and I have to deal with it... you just take care of business and get on with it... you're looking at 10 months for all that to heal up... Then you're gonna have some rehab on top of that. Just grin and bear it and work hard.	I'm totally comfortable here at this facility. All the people are very good. They do their services to the people that are here pretty much on timely schedules and within an acceptable range of... as far as doing a complete job and on time. The facility here is just beautiful... It's been really good... Seven actually is probably a conservative number but I...
UM-041 Male White 60/1ysi Medical Comp Para Other priv No caregiver VETERAN	Retired. Divorced. Lives alone. Had an aneurysm; paralyzed during the surgery. Has 3 supportive children. Has grandchildren. Response Shift: 0 Quality of Life: 7	This is something that you have to learn how to do by yourself. There's not going to be anybody there to help... Well, I think that I was used to living alone. I think that that probably made this a little bit easier... I know things could be a lot worse... So it doesn't take a whole lot to see that things could be worse...	The whole thing still at this point is kind of a learning thing. And still hoping like heck that everything eventually gets better.... And it's going to take a while before I quit hoping that... I think like you said humans just adapt to the situation you're in... Everything you did was a chore. Everything. But you figure ways out.	...life is kind of blah right now. I've watched more TV since I've been out of the hospital than I've seen in years... if I don't get my legs back, it's just awful hard to see how things can get a whole lot better than where they're at right now. Which I know they can... I think that it [bladder and bowel] definitely messes up your quality of life.
UM-042 Male White 55/1ysi Fall Incomp Para Medicare No caregiver	Married. Was separated at the time of injury. C5-C6 injury. Walks with a cane Response Shift: 1 Quality of Life: 2	Well, yeah, my life's way more difficult than just this injury; but it's like the icing on the cake. It just – everything got taken from me and then now my health. It's just unbelievable. I lost everything... like fuck, you're counting every penny and it's – and now I'm like one of them and I don't want to be one of them...	Now we're out here. So I have no idea of where I would be if I – I can't even think that far. I used to fear the future even when I had everything in the world going for me... now I don't even think about it... to think that I'm going to live the rest of my life like this is not good... but in totality, you know, it's still minor thing.	I always look at – my friend tells me... things could even get worse and as a matter of fact they have over time. I don't know because mine is probably relatively minor maybe compared to some people... Finding something I truly love to do which I've never found... I don't even like to think about the next day.
UM-043 Male White 33/1ysi Sports Incomp	Recently divorced prior to injury. Injured during a workout using a pull-up bar. Now living with parents. Response Shift: 2	I just kind of roll with the punches... And then after a certain point, then it just becomes kind of normal... I guess I dealt with it pretty well, but I could see how some people wouldn't be able to deal with it too well... Everyone says this is a	It is what it is. You do lose all that modesty of just being embarrassed about it because it is just a part of your life and it's going to be a part of your life for the rest of your life. You can't hide something like that... I guess it really hasn't changed my	...actually having people there by your side; that definitely helps. I don't know why I took it so well. I'm not really too sure. Like I said, I was ready for a change anyway, and maybe this is just the kick in the ass that I needed. I don't know... It's a

Tetra Other Priv Caregiver	Quality of Life: 6.5	permanent deal... It's kind of up to you to try to figure out how to make it better... That's really the biggest change is having to rely on people... realizing that was one of the hardest things.	goals; it's just made them more important. All my goals are still the same... Yeah, it has motivated me a lot more to be a better person.	big change, but I don't think it really changed my quality of life too much... once you get everything in control and you start understanding everything, then it becomes less of an issue.
UM-044 Female White 27/1ysi Medical Incomp Tetra Other priv Caregiver	Unmarried. Dating someone since prior to injury. Currently living with parents. Diabetes ketoacidosis, which then led to a stroke to the spinal cord. Response Shift: 1+ Quality of Life: 7.5	I'm still hoping that I can walk again and I'm you know, I'm very determined. I'm very strong-willed and sometimes stubborn so I'm not going to give up... Things happen for a reason. For some reason God wanted me to go through this process. I mean maybe I'll learn something... I mean me bitching about it and me being sad is not going to change the outcome.	But I mean everything just changes. You look at everything differently. Just your outcome on life you know, you start to appreciate things better... I used to run all the time which I don't run anymore, but I've picked up new [hobbies] that I haven't done before. Like I started painting at therapy because it was working on my hands. So I mean I picked up painting which I never did before.	I try to see the positive in anything and I you know, my hands are moving more now. I have more – my vocal cords, like everything's working. So if I keep telling myself I'm really good, maybe one day I'll believe it you know, sort of thing. So I mean I'm not the best but I'm not the worst...
VA-002 Male White 45/20ysi Vehicular Incom Tetra VA Caregiver	Lives with his wife. Currently employed. Injured in motorcycle accident. Military background (Marines) but no mention otherwise. Injury inspired him to college. Response Shift: 2+ Quality of Life: 8.5	...it's just a matter of timing things out... It's a procedure to get in there, do the catheter, and get out, you know can't be rushed... if everyone is going out bar hopping or clubbing or whatever, I don't go because I'm not going to be out running around. I need to be able to find a restroom... I'm a much more empathetic and understanding person than I ever used to be.	I still write left-handed, I still put pants one leg at a time, but not much that didn't change. I still like doing the same things I just have to do them differently... they used to have a shrink come in and talk to us... she kept telling me, you're going to go through a depressed phase. About three months in she goes, you know I don't think you're going to go through it... this is what I have to live with and I'm too young to sit here and rot.	Because for the most part I'm pretty happy with the way my life is.... I have a good job, I have a good wife, my kids are healthy, fairly intelligent, not killing each other yet. So yeah, for the most part life's pretty darn good. Could it be better? Sure, I could wake up tomorrow and have full bowel and bladder control. Not going to happen... Things could be always be better and always be worse... my spinal cord injury altogether changed my life goals.
VA-003 Male White 35/13ysi Vehicular Comp Tetra VA Caregiver	Injured in a car accident. Married, one child. Seemed guarded in interview. Served in Air Force; injured while enlisted. Response Shift: 1 Quality of Life: 8.5	You go from being self-sufficient and doing what needs to be done to depending on people around you...I've been pretty fortunate from baseline of injury to now... As I talked to urology more and more, I said why don't we make it a constant drain and be done with it? So that's what we ended up doing... But that's me, everybody's different.	I have a system now... It hasn't changed me. I mean it is what it is... You have to have the drive to do the things that you want to do. If you've got no drive, you're just not going to make it. You'll become that recluse, that person that hides from their problems... I mean just that drive to never give up. That's just the way I've been. If there's something you want to do, there's a way to do it.	You know, there's things that could always be better. But they could always be a lot worse... The time I get to spend with my son. There was a lot of years that I wasn't around him.

VA-004 Male White 43/10ysi Sports Comp Para VA No caregiver	ATV accident. Had bladder augmentation surgery 4 years go and likes the results. Divorced and has a daughter. Was in the Army 4 years after high school Response Shift: 2 Quality of Life: 9	About 6 years ago... I came to the point where I didn't care (about bowel accidents). If it happens it happens... And I guess try and become more in tune with your body... Basically I don't want to get in another relationship... I'm content with being able to do whatever I want, whenever I want, however I want... I'm pretty content with the way things are right now.	Just getting on with life basically. Not letting that aspect of it (bowel and bladder) control my life... I am not going to let it control my life. I'm going to live my life. If I have an accident it happens. That's my attitude now... At first, yeah it did affect me. But now, I know it sounds weird, but I basically don't even consider myself in a wheelchair now... Not to let it control your life.	Because if I said 10 then there's no room for improvement... My daughter, the dog definitely helps improve my quality of life. I don't know. That's kind of a tough question. I've never really thought about it.... My daughter, the dog definitely helps improve my quality of life.
VA-006 Male White 57/36ysi Vehicular Comp Para VA No caregiver	Married and divorced twice post-injury. Injured in a motorcycle accident. T-5 injury. He was a radio technician in the air force. He is currently retired. Response Shift: 2 Quality of Life: 7.5	...there was a huge ward of all these other spinal cord injured people, and most of them were worse than me. So I started thinking, I could definitely be a lot worse off... I've never been one to give up... I don't want to give up on it, I want to get it done... (family) say I'm the strongest one... maybe part of that is I don't want to let them down.	Like I usually tell people, you have to play the hand you're dealt... I guess I feel stronger in a way. You know just having to deal with a lot more than I've ever had to deal with, or that the average person has to deal with as far as that kind of stuff... it's an independence thing. You want to be able to prove that you're still able to get along on your own... to enjoy life.	Because it's certainly not a 10, but it's pretty good. There's things I got to deal with but that's just the hand of cards I'm dealt and I have to make the most of it. I'd like some things to be different, but I'm glad that a lot of things are the way they are too, you know... It's a significant change in lifestyle that you have to make allowances for...
VA-008 Male Black 48/26ysi Vehicular Comp Para VA No caregiver	Married for 22 yrs. T5-6 Spinal cord injury. His caregiver is his spouse. Has 2 children. Is a professional photographer. Response Shift: 2 Quality of Life: 10	I actually picked up my wheelchair and I threw it across the room. I sat in bed and I actually cried. I was like why? Why is this? Why is this happening to me? At that point, the tears turned to laughter... I just had a moment with God, I just said you know what, I'm tired of this. I just can't take this anymore. I heard a voice that said don't worry about it, I got you.	...I'm not embarrassed about that anymore... Once I learned my body and accepted that this is my life, that's how I dealt with it... they see me as the normal dad. They don't know anything different. I still cook. I still got to wash the floor... I'm at the basketball games. I'm at the football games... They don't look at me any different because I'm in a wheelchair.	I wouldn't change anything. I got two wonderful boys. I've been married over 20 years. My life is perfect. People say that, like I said, being in the chair is not the hard part. Once I conquered dealing with the bladder and the bowel, once I conquered that, I never looked back.
VA-011 Male Black 48/16ysi Vehicular Incom Tetra Auto NF Caregiver	Married with 3 adult children and two children in high school. C5-C6 injury, has some sensation and can walk a little. Response shift: 2 Quality of Life: 9.5	...early on it all is quite overwhelming... So there's a lot of exploring your mind and wondering a lot... Because there's so much to take in, don't try to figure it all out right now... I was raised in a Baptist church. And to tell you, it was just a spiritual journey for me, it really was... Having a strong intact family, network has been a source of comfort for me.	I realized that my situation could have been much worse and I'm thankful for what I have. And really coming to a place psychologically, this was the problem and the key, to understanding that being in wheelchair does not make me less of a man or a human being. Once I was able to deal with that... I was in a good place and I was able to move forward with my life...	Just the place I am now, I'm happy, I'm fairly healthy, my family is in a good place. I'm in a place where I can give back. I can give to others and make a difference in other people's lives which is something I've always wanted to do. So I'm there now. So I think to me that, for me that quantifies success.

VA-012 Male White 56/27ysi Vehicular Comp Para Other Priv No caregiver	Unmarried. Lives alone. T5 injury. Car flipped over on his vehicle. Employed as an executive director of a spinal cord injury organization. Response Shift: 2 Quality of Life: 9	... my coping skills and my attitude when I look back on it, I've always been a positive person... And so the adjustment period for me wasn't as difficult as it was for other patients... I go and see people in the hospitals that are in far worse situations... I took a situation that I wouldn't even wish on my worst enemy and made it work... So I controlled the injury, I didn't let it control me.	Well I was devastated. At first I didn't believe it... then it hit home for the first time for me that this was the way it was going to be... you move on and your goal is to try to do what is necessary so you can eventually go home and get on with your life again... I've learned a lot about myself... I was given a hand and I was able to make it work, everything work for me.	The reason I didn't pick 10 is it's not perfect and a lot of it revolves around the bowel issues. It's just as I said, as I've gotten older it starts to control more of what you do, in terms of you controlling it. [Regarding auto coverage] So either way we are blessed. We get the supports necessary to make it work. The ones that fall through the cracks are the ones that have a difficult challenge ahead of them.
VA-013 Male White 56/37ysi Fall Incom Tetra VA Caregiver	Injured by falling. Has had a consistent caregiver for 15 years that turned into a romantic relationship 5-6 years ago. Retired computer programmer Response Shift: 1 Quality of Life: 8.5	I go to church every now and then. Volunteering, I guess I volunteer, but I don't volunteer on organizations or things like that. Somebody may ask me to help them out, I guess that's volunteering... But you know things like that, just an everyday thing... Being young I guess because the younger you are the more accepting you are.	It wasn't so traumatic. I don't think I went through a lot of traumatic experiences learning as some of the other people did... if it's gotta be what it's gotta be, let's get on with it... that's a part of life. You have the same things that I do except that you can do it a lot easier than I can...I accepted it. I wanted to look forward and do what I had to do to get on with life I guess.	Why? That number, I don't know. It could be a little better. I could be in Florida, not in the cold. I could be out traveling. But overall, every day I say a prayer and I thank God for the life I have, for everything I have, for my family and my friends. So I'm pretty, I'm thankful because I'm happy with what I got despite my injury. I think I got it pretty good.
VA-014 Male Hispanic 62/33ysi Vehicular Comp Para Other Priv No caregiver	Married. T11-L1 injury. Hit by a truck while walking. Was a Navy corpsman taking care of spinal cord injuries. Employed full-time at GM Response Shift: 2 Quality of Life: 8.5	My military background and my medical background really, really helped me overcome all my disabilities and depression and denial... A lot of people take years and years to get over that... you're going to have to pick up your pants and put your boots on and start over. Because once you hit rock bottom there's only one place to go.	If it comes to the point where I can't take care of myself I'd rather that I wouldn't survive... Why me?... I knew there was never an answer to it so I just moved on. It didn't take me long... It's just going to determine how I move on down the road. I knew there was nothing I could do to change it... it was a done deal and I had to make the best of it.	Because I have a job and I'm healthy and I make a lot of money... Free time and to do leisure activities... I'm looking out for me. I want to get myself back in shape because I may not be able to walk around but I'm healthier than most people out there... I'm in really good shape in that respect, you know. So I want to take care of myself and go out and I love physical exercise.
VA-015 Male White 67/13ysi Vehicular Incom Tetra VA Caregiver	Unmarried. Three adult sons. Ex-wife acted as caregiver briefly after his girlfriend died in a motorcycle accident. Has some mobility. Response Shift: 1 Quality of Life: 5	And the good Lord said to me, "Now I've got a good handle on you. I don't have to worry about where you're going because I know where you're at now all the time." So this is the Lord's way of saying... it's slow down time... Regardless how bad you are... there's always somebody around the corner somewhere that's worse than you are.	I don't think a whole lot. I mean I still have my sense of humor and it's not like I've lost it... it hit me pretty hard. But on the same hand if you turn it over... If I had lost my sight and boys, I would be in a corner some place with a rope around my neck... The good Lord knew what he was doing. He hurt me just enough to make me slow down...	Well it balances because you've got that balance. You've got to have the feeling that you can still do what you want to do but on the other hand you've still got that little bit of pressure pushing down on you just saying just chill out because you're right at all you can do. There's no need to get anxious and think that you can do something that you can't do.

VA-016 Male White 58/28ysi Vehicular Comp Para VA No caregiver	Injured in a motorcycle accident. Suffers from lymphedema. Self-employed as a "dog behavioralist". Response Shift: 0 Quality of Life: 7.5	I'm not asking God to walk, bowels and bladder would be nice. They say this is incurable... I can't believe the creator of everything made something incurable... let's put it this way, if I ever got down, if I ever got blue, or if I ever gave up it would probably crush my family... I ever quit trying, it would probably kill them....	You can't stop me. When you become paralyzed you either got to get into life or not... But yeah, my goal is to do dogs. And I don't do a lot of them. I just, over the years I've done hundreds... Well I was raised rough and tough on a farm. I was raised around tough men and tough everything... And I've been fine ever since.	...I don't ever give up. I don't ever surrender. I never give in no matter how bad it feels... But again, that's just everything combined into itself so it's just something you have to live with so I can never be so-so. I've never been in the middle. I've always been to the better, always been to the better.
VA-017 Male White 45/26ysi Vehicular Comp Para VA No caregiver	Hurt while in the Marines. Aircraft mechanic. Married well after his accident and they adopted two boys. Response Shift: 1 Quality of Life: 8.5	I just needed to prove to myself and everybody else that I was independent... there was a lot of quadriplegics [on his ward] that couldn't take care of themselves at all... I've always been like that. There's no sense in getting upset over something that you have no control over. I think one reason that I accept things so well is because my accident was nobody's fault but my own.	Just to see how far I could push everything. It made me feel more alive. But that's why I never thought I'd live past the age 40. But now, I'm married with kids and everything has changed... I have accepted who I am in a wheelchair... I don't really think about what I've lost. I just think about what I can do, what I can still do and what I still want to do and how I can accomplish that.	Well because things could be better. I could have more money. I could have a better job. Things could be a lot worse, but I think things could only be a little bit better. Things are pretty good.
VA-018 Male White 57/36ysi Vehicular Incomp Tetra VA Caregiver	Was a sergeant in the Army. His sister is his main caregiver. No relationships or friendships other than family. Response Shift: 0 Quality of Life: 7	[Regarding bowel program] So if that's what's got to be done, then it's got to be done... You have no control over your own life... you always have to depend on somebody else do something for you... It's just something that you have to deal with, so you do. You could die but then you'd say, damn you're going to miss the soap opera tomorrow. [Military] You had a sense of accomplishment.	It doesn't make me feel any worthless or worth more, so it just is what it is. When you've lived with it for this long, you just say, "Shit happens, sometimes more than not." But that's the way it is. When people wear the t-shirts "Shit happens", that's literally my life... it's a hassle and it wears on your nerves and sometimes it can be embarrassing. That's just something you learn to deal with...	I do anything I want to do. I'm sure that if I wanted to do something that I could get somebody to do it with. Like if I wanted to go on a trip somewhere I'm sure I could get somebody to take me, if I wanted to. I am financially secure so I have no worries about that. My life is pretty good altogether. I mean the way I, to somebody else it might not seem, but I can't live for anybody else.
VA-025 Male White 65/26ysi Vehicular Incomp Tetra Auto NF No caregiver	Injured in an auto accident. Married to the same woman throughout. 2 children. Medic in the Air Force. Response Shift: 1 Quality of Life: 6	... his injury being so complete he really needed care 24 hours a day, seven days a... I had such a good recovery where he had really rough recovery and needed a lot of help... I wasn't an A Type personality. I wasn't the real aggressive go-getter, got to win every game type of person. I was more the type of personality that could go with the flow...	On many of the days, especially the days with a bowel movement I will say I'm more depressed and more ornery...in a way it reduces your sense of self as little belittling. You just feel that it takes up so much time. It's ugly to deal with. It's painful to deal with especially the bowel and it's just... it just takes a lot out of me... I just don't feel as good about myself.	I do feel down. Quite often I do get depressed about the situation. I feel following spinal cord injury I'm so limited as to... I'm much more limited as to what my options are... It's just not a great shiny outlook... I don't like the idea of someone having to take care of me on a regular basis and yet I know if I live long enough and chances are that will happen.

VA-026 Male White 64/45ysi Vehicular Comp Para VA No caregiver	Injured in an auto accident while on active duty. Divorced. Never worked. Step father to 3 sons. Been living alone for 25 years. Response Shift: 1 Quality of Life: 9	It was pretty devastating, but I had no choice and I had to adapt... I just put everything out of my mind and got into drugs the first couple years... Accept it and move on or take the path that leads to no good... When I was paralyzed I was independent, everything was going ok... But it's to the point where it doesn't really even matter anymore.	I calmed down a whole lot actually a long time ago... Just growing up, I guess... You can't sit around and say woe is me. You have to wipe your butt and get out of the house... Well I really had no idea. I just accepted my situation and that was that. It was all out of my control and there was nothing I could say or do to make any difference. It's either hang in there or die.	Well it's because I don't care anymore. I give up. I'm not depressed. I accept my life, that's all... I know how it is and how it has been and that's the way it is... So I don't think about it or worry about it... Well, it sucks. It's a struggle, but it's ok... Yeah I just live with it. I stick to the plan... Yeah and for my life. Get your little butt up and try to be happy...
VA-027 Male Hispanic 72/29ysi Fall Incomp Tetra Medicare Caregiver	Work for Ford and as a landscaper. Injured falling down stairs. Married. His wife helps with his care, since he cannot cath himself. Has other paid aids. Response Shift: 1 Quality of Life: 4.5	First two, two-and a half years were real rough for me though, trying to accept being in the wheelchair... it took quite a while, but after that I more or less accepted that I was going to be like this... a lot of people couldn't accept it either, they were kind of shocked. They didn't know how to go about it, trying to talk to me about it.	Well I figured that was the, when I was born, that was the route that was already made for me. And this is the way I have to stay like this and there was nothing I could change. You either accept it or deny it and then just be miserable... How do I deal with it? More or less I think you try to ignore it I guess... I think it has me changed some...	Because everything else, we can go any other place and it would be more or less the same but it also takes money to go out. Like I said, we always used to go and now you have to watch it like how long you can go... Well, being with my wife. She's stuck it out with me through all of this even though she gets grumpy every now and then.
VA-029 Male White 55/17ysi Violence Comp Para VA No caregiver	Parents/wife all died over a five year period, leading him to substance abuse to cope. Has a hard time maintaining employment due to bowel. Response Shift: 2 Quality of Life: 6	Well I was lucky because I had previous medical experience. I knew what was ahead of me... Knowing it and accepting it are two different things, it took me a while to come to grips with it... I don't know what it was inside people that make some people give up and some people fight... I was adamant about that, like I'm not going to let this change me or change who I am, define who I am.	...the things everybody wants in life, love, family, that's over. That's not going to happen for me... So I've just accepted my lot... And knowing it in your head is confidence, 90% of it is confidence... It's hard to accept, I just didn't want to live at first... But after a few weeks in the hospital, once I got up and around... and seeing that life goes on... I'm not going to let that guy take my life away.	At this stage, at age 55 I don't have much time left on the planet. I'm not going to be starting a family. I'm not going to be, so those things are gone, but that doesn't mean that there's not still something to live for. Yeah, I've missed out on that and I've come to grips with that. I'm ok with that. For whatever reason, that's the way it is.
VA-030 Male White 64/21ysi Medical Incomp Tetra Other Priv No caregiver	Works as a hospice chaplain. Seems very fixated on his bladder and bowel issues. Holds himself to his old standards. Naval Reserves. Response Shift: 0 Quality of Life: 8	...I'm pretty open. I'm not afraid to tell people if they ask. I'm not ashamed of it. Smelling like urine can sometimes be disheartening, especially when I'm visiting people because I'm a hospice chaplain... My wife wants no part of it... My wife is kind of a germaphobe... I don't want or need her to be... Other than that, nobody really knows a whole lot...	No, I try to keep it as private as I can. I'm not ashamed of it or anything, but I try to be as private about it as I can... Well I have the job I wanted, doing what I want to do, as long as I can keep well... I'm pretty good with myself. I'm not afraid of it... I'm pretty well balanced out and God has given me the grace to do what I do...	Because I like what I'm doing, I like my life. Everything would be great if I didn't have bladder and bowel problems. But I'm not going to let that affect what I do and who I am... My work, getting in to visiting people who are at the end of their life and being a part of who they are and what they do... God gives you the grace to do it, to do what he asks you to do...

VA-033 Male White 69/27ysi Fall Comp Para Medicare Caregiver	Highly supportive wife and strong military background. Injured when falling out of a tree while hunting. Has 2 daughters, 12 grandkids. Response Shift: 2 Quality of Life: 7	I had to learn to do everything for myself. My wife helped me a little bit, but as little as possible, so I could become more dependent on myself than her. We made the adjustment and it has worked... I've seen a lot of guys that had accidents, diving accidents or something, where life, they were right on top... Just the fact that I love the Lord and I think he helps me through a lot... you get a strength from that where you think things are going to be better someday.	I guess because I want to feel as much of a man as I can. I realized there's things that I can't do now that I used to do. But I never let that get me down... I don't think it has changed me as a person. I'm the same person I always was... See I don't get up in the morning thinking oh God, I'm paralyzed. Because if I do think about being paralyzed it can get to me. But I get up in the morning thinking well what am I going to do today?... I feel like my life is still complete to a degree.	...it's the fact that I can go through and say 8 or 9 but I won't say 10 because it's senseless to say that you're at 10 when you're in a wheelchair. Well I picked a 7 because it's not just so-so, so I picked the one right after it... Well I could have went for an 8 or 9 but the fact of the bladder having to get out and make sure that you have this and that to do the bladder and your urine and everything like that.
VA-035 Male Black 62/28ysi Violence Comp Para VA Caregiver	Unemployed. Paralyzed via gunshot. Has 3 sons and 4 grandsons. Credits the VA with taking very good care of him: Response Shift: 2+ Quality of Life: 10	I didn't know anything really about being paralyzed when I first got shot but I had a friend of mine that was paralyzed. So he was teaching me... I know what I have to do to survive and I'm not the only person, I wasn't the first one and I'm not going to be the last one... When I got shot, I had a good attitude... My survival skills because I had to learn that when... I was in the infantry... I believe in Jesus Christ... and positive people around me that are helping me... I'm independent.	I'm adjusted to this. I've accepted the condition I'm in because it could be a lot worse... some guys in wheelchairs they confine themselves in, they confine themselves away from people.... But I'm not that type... I still knew who I was in the wheelchair. It was not like I'm living in it, I'm just using it. I don't sleep in it... I guess they see me in the wheelchair and they just see a glow in me. They just see me with a smile on my face...	Because I feel that way and I'm living that way... Just looking at TV, looking out the window, minding my own business, minding my P's and Q's... That I'm alive and still in my right mind... It is a good thing. A lot of people didn't wake up this morning; they didn't wake up in their right mind either.

Response Shift-Quality of Life Thematic Analysis

Response Shift Theme	Description of theme	Connection to QOL	Subjects with this theme
Behavior-driven response shift	Shows particular determination to take an active role in redefining social roles, finding and maintaining employment, processing through the injury and actively building a quality of life for themselves; includes reconceptualization of QOL and a shift in internal standards. Redefines self but also adds new behaviors. Includes: change in behaviors, reconceptualizes roles in life, positive affect, shift in standards	Accepting can no longer do all the same tasks as before; cites room for improvement but overall happy with life circumstances. Empowerment, efficacy over decisions, seeing the positive, and cites the “good” things about life. Ability to reconceptualize their lives and take action is either caused by or results in higher QOL ratings – some cite support leading to new behaviors and therefore improved QOL, others cite their adaptation being fueled by a good QOL thereby enabling their response shift. Bladder and bowel are rarely cited at all.	UM-012; UM-013; UM-014; UM-020; UM-040; UM-044; VA-002; VA-004; VA-012 Total: 9; Vets: 3; New: 2; Female: 3 Average QOL: 8.28 Average RS: 1.67
Awareness-driven response shift	Shows particular focus on reconceptualization of self, new sense of who the person is following their injury, but little to no shift in behaviors beyond what is necessary to live with an SCI and manage bladder and bowel. Talk of being a better person, growing up; changing internal standards and values regarding self. Includes: general positive affect, shift in standards, self-improvement	Discuss some achievements in the past, no “real” problems, and not being hopeless. Cites strong family support or making comparisons that their lives could be worse like others they know. Optimistic that their lives are better than average. Talk is more around what they have, then what they hope to do. Being in a “good place”. Response shift and higher overall QOL results from the supportive environment they live in, the “blessings” they possess, not so much their self-determination or goals they hope to achieve. Bladder and bowel are obstacles but they are manageable.	UM-008; UM-009; UM-010; UM-017; UM-023; UM-039; UM-043; VA-008; VA-006; VA-011; VA-014; VA-017; VA-033; VA-035 Total: 14; Vets: 8; New: 3; Female: 1 Average QOL: 7.89 Average RS: 1.71
Social comparison	Recalibrates their sense of normalcy or acceptance through social comparison with other people or other potential circumstances. Some talk around family or outside forces being their motivation for acceptance and “learning to live” with SCI. More talk of depression and hope that things get better. Could be worse. Includes: new normal, acceptance, external factors in coping/adapting, social comparison	Social comparison keeps their sense of QOL in perspective. Cite often how they retain their sense of self, how life is neither all good nor all bad, but in the middle. Some find it hard to see things getting better in their lives. A few count blessings and cite opportunities to be with family more. In general, thankful like the group above and speak a lot of balance – how things are balanced in their lives. One cited fears of the future, depression, and being overly dependent on others. Some directly cite bladder and bowel as having a negative impact on QOL.	UM-021; UM-030; UM-041; VA-003; VA-013; VA-015; VA-016; VA-025; VA-029 Total: 9; Vets: 7; New: 3; Female: 2 Average QOL: 7 Average RS: 0.89
Resignation	A clear sense of being “stuck” with little to no apparent response shift. Fear or lack of concern for the future. Focus on loss of independence. Expectations are not redefined, except where they are abandoned. Also may try to ignore their issues or other problems. Avoid social engagements. “That’s the way it is”. Includes: less positive affect, lack of response shift, sense of loss, passive acceptance	Cite loss of mobility, loss of independence, bladder and bowel more frequently. Show some perspective on things “could be worse” or “could be better”. Talk of acceptance; being able to do what they want, if they wanted to do it. Some family support. In general, like the group above, there is little to no talk of proactive self-determined action to improve life. QOL is through an acceptance of the circumstances, some wishing for improvement, but little sense that circumstances will improve.	UM-005; UM-018; UM-038; UM-042; VA-018; VA-026; VA-027; VA-030 Total: 8; Vets: 4; New: 2; Female: 2 Average QOL: 6.25 Average RS: 0.75

	Antecedents	Mechanisms	Response Shift	Perceived QoL
	Stable or dispositional characteristics of individual, including demographics, personality, expectations, and spiritual identity.	Behavioral, cognitive, and affective processes to accommodate the changes in health status (catalyst), e.g. coping strategies, social comparisons, seeking social support, reordering goals, reframing expectations and engaging in spiritual practices.	Defined as change in the meaning of one's self-evaluation of QOL as a result of <u>changes</u> in internal standards, values and the conceptualization of QOL. (Essentially, the result of antecedents and mechanisms responding to catalyst).	Multidimensional construct incorporating physical, psychological, and social functioning. (Essentially, patient reported QoL in summary, including overall happiness/lack of happiness, wellbeing, etc.)
UM-042 55/1yr RS= 1 QOL=2	Now walks with a cane, fingers and feet numb, cannot move toes. lives with his wife /wife's mom. Has a very limited support system disability lost his job.,Alcohol issues	Well, yeah, my life's way more difficult than just this injury; but it's like the icing on the cake. It just – everything got taken from me and then now my health Had half a million dollars four years ago now nothing and I'm broke and I have a credit card debt and we just this month	But as far as my bowel and bladder issues, they are not keeping me from doing anything... use to fear the future even when I had everything. Yeah, but I would have to say, you know, your life can always get worse but I don't know how worse their life	I found out for some reason... I've got a full gym me try to educate myself by watching things on YouTube ...time with my wife.... Find something I love to do and be able to contribute,...helping other people and ...some kind of a small living out of it. Other than that I'm, I don't even like to think about the next day.
VA-027 72/29 RS=1 QOL=4.5	Has a colostomy for the last 2+ years, which mostly eliminated accidents wife helps with his care, since he cannot cath himself. Has other paid aides Gave up a lot of his life work, leisure activity	just drink enough to keep me hydrated and that seems to work. I can go 8 or 10 hours without being cathed by just limiting how much I drink. <i>Regarding sex</i>] Right. Oh, we tried different thing. Gave up photography and woodworking	First years were rough...after 2&3 years more or less accepting. ..mostly wanted to stay in the house. Other than...difficulty in talking with others.... How do I deal with it? More or less I think you try to ignore it I guess. That's something that can't be done.	Like I said, we always used to go and now you have to watch it like how long you can go. [Wife] She's stuck it out with me though she gets grumpy every now and
UM-030 45/1 RS=0 QOL=5	HIV Positive. previously taken classes for a certified medical assistant .	I don't go out as much. I used to be a people person. I just loved to go out, I just don't go out as much, and just not talking, the interaction. have seen a lot worse than me and I think that kind of made me feel like "Oh my God, why did this happen to me? it's like being a baby all over again, learning how to do	part of the spinal cord injury and it's just something I have to deal with and figure out what I can do to fix it. It's hit me hard. But I'm going to do what I can do, and I'm happy .But it's discouraging. It's more pride than anything, but I got to look at it and say it's an accident.	I'm happy with it, but I want more. I wanted to -- I want it to be more happy... Being able to get out more and go see people, get my mind . kind of still working on the house to get it so I can get everywhere and the more we work on that the happier I get...I'm getting more independent on -
UM-038 36/1yr RS=0 QOL=5	Had Botox which has stopped bladder leakage. Does not go out in the community other than for appointments since injury	You have to rely on somebody to get you, you have to take pills to go poop. I'm going to go to the bathroom so I let my caregiver know that I'm going to go so that he's aware... I wear a diaper 24/7...I feel like a very, very old person in a diaper This is new to my whole family, we have no people impaired in wheelchairs,	Basically I'm starting over... first day home I couldn't reach my stuff on the kitchen table and now I can. I couldn't put a cup in the sink and now I can. Pour a cup of coffee, now I can. I just figured new ways...doctors need to work on some stuff and give me my legs back	The doctors need to work on some stuff and give me my legs back where I have to rely on people to take care of me. I don't like that... Just getting used to the lifestyle.
UM-041 60/1yr RS=0 QOL=5	...aneurysm in his abdomen and became paralyzed during the surgery for Moved to a new home that is wheelchair accessible,	When I got out of the hospital, I had my daughter stay two nights with me, and after that I said, <i>that's enough.Moved to accessible housing post injury</i>] Well I know things could be a lot worse [cites a number of people with disabilities	...still hoping like heck that everything eventually gets better... And it's going to take a while before I quit hoping that. [Hopes to gain back full functioning in legs bowel and bladder] cites things that she use to do that she cannot do anymore	life is kind of blah right now...I think that it [bladder and bowel] definitely messes up your quality of life when you can't pull your own pants down I think I'm pretty lucky on my bladder...can cath myself in my wheelchair if I have to. So I don't think it's affected me as bad as the bowel has.
VA-015 67/13 RS=1 QOL=5	Unmarried. Three adult sons. Married three times previously. Ex-wife acted as caregiver briefly after his girlfriend died in a motorcycle accident. Has some mobility.	So yeah it hit me pretty hard. But on the same hand if you turn it over, I would rather it had done what it did do than lose my sight and my boys. If I had lost my sight and boys, I would be in a corner some place with a rope around my neck	So if you were to say, what was your life like 10 years ago? My life was basically the same as it is now. I mean I still got two legs and two arms and I got a little bit of movement in both of them. So there you are.	Pretty close. I mean because right now, I'm balanced. I've got, I know what the problem is. I know the reason why I'm here. And that's where I've got a little bit of an edge on some people.
UM-012 56/12 RS=2 QOL=5.5	Credits his physical fitness and endurance prior to accident as important now.. Does not make comparisons with others. Normalizes his bladder and bowel. reframed his career as a manager into a leadership and parenting role in his family	it's actually allowed me to spend more time, when my boys were younger when I was first hurt...have some exercise equipment at home if needed, if something ever happens. This way I could continue to exercise because I have found that it has created endurance for me and the to cook dinner.	personally now for me after 13 years it's not so much about the sex as it's about finding other ways to love your partner in other aspects of life. .. <i>Exercise</i>] That's probably my normal...that's who I am. I've always exercised prior to the accident	It actually is a day to day schedule that many individuals that are not disabled actually can take for granted. It's just more of a situation that just really disrupts the day. I mean, the bladder I can get around that even though I've got to still look at a clock. But the bowel program just...it just disrupts your day.

	Antecedents	Mechanisms	Response Shift	Perceived QoL
UM-023 57/1 RS=1 QOL=5.5	Could not walk initially...now walk with canes. Doc said ...will continue to gain back walking ability... lost B & B function...gaining some bowel muscle control	it's like being a baby all over again, learning how to do, but it's harder because a baby it automatically comes to...even though I was in bad shape at least I was walking. ..	never did [go out] even before my accident. I didn't go too many places.. I've got a cell phone –lucky if I make two phone calls a month on it. I don't talk to too many people.	You're always going to be able to find somebody that's better off than you are and people that are probably worse off than you are.
UM-010 35/16 RS=1 QOL=6.0	INJURED AT YOUNG AGE- GROW UP FAST	Not being able to walk is not as problematic as not being continent Each year learns a little bit more about what he can eat or drink	More picky about relationships More honest in his assessment of self	Social comparisons-sees self as better than some. Not hopeless, but has regrets.
VA 025 64/26 RS=1 QOL=6.0	I think I had a very good support group. My wife is very strong	almost more devastating [than] the inability to use my legs and more was that of having to be catheterized and to develop some sort of a bowel program. ... <i>sexuality</i>] I really at this point, it is important to me but I really miss it. I don't really do anything with it.	lack of bladder and bowel control ...a greater problem with SCI than lack of mobility is...part of deficit that eventually can really drag you down. More depressed on bowel days...not as happy with myself...more depressed more often now with the bowel	all in all really a happy person except on bowel days I'm much more limited as to what my options are...don't like the idea of someone having to take care of me on a regular basis and yet I know if I live long enough and chances are that will happen
VA 029 55/17 RS=2 QOL=6.0	Parents and wife all died over a five year period, leading him to substance abuse to cope Has a hard time maintaining employment due to bowel issues	Involuntary bowel movements...one of the more difficult aspects of the whole thing, I mean other than the inability to walk..... Knowing it and accepting it are two different things, it took me a while to come to grips with it... Military experience ...I was adamant about that, like I'm not going to let this change me or change who I am, define who I am.	the things I want in life I'm not going to get.--love, family. Not using my potential .fell back into using drugs again ... but.... made me sick to my soul. I did it a couple times but I was like this is wrong	It's health and I guess just gratitude of being here... Well it's not much of a quality of life... I have to, those things were kind of jerked away from me rather abruptly in other ways than just my injury.
UM-039 42/1yr RS=1 QOL=6	Divorced. Obese but trying to lose weight. Credits faith in God and wanting to be an inspiration to others as help in getting through injury. Has a 7 year old son that looks up to him; takes that as motivating.	So I feel really fortunate that I am here and I am sitting in this regular chair talking to you. I'm not paralyzed from the neck down...It plays on you emotionally and mentally when you can't control your bowel function ... I was terrified of a catheter ...but I got used to catheters The same with bowel	I've been programmed to hurry and wait...that's the whole military style...you hurry up and you wait for us to tell you what to do...so this injury has been kind like a hurry up and wait. Because it's just a process. "'During the first few month of my injury, you know, depression	Well, because before I got hurt I would probably have rated myself at eight... You know, just because I still wasn't as physically fit as I could have been, you know. So, you know, I'd say a six because I'm more than half better than when I first started, when
UM-043 33/1 RS=2 QOL=6.5	Recently divorced. Injured a few months before interview ... Lived a physically active life prior to injury. Self-reported as independent prior to injury. Going from doing all that to doing nothing is a huge difference.	...just roll with the punches... And then after a certain point, then it just becomes kind of normal...definitely uncomfortable. No one really says that it's ever going to get any better... always independent....is having to rely on people for pretty much everything and realizing that was one of the hardest things.	There's nothing worse than having accidents all day...it is what it is... You just have to deal with it. You don't have any choice. I guess it really hasn't changed my goals;.... I still want to succeed in a career...	Best things .. Being close to the family Worst thing Being so dependent on everyone else that's really difficult. Especially when you're so independent
UM-018 30/10 RS=1 QOL= 7	Worked as a web developer from home post-injury. Volunteers at National Organization for the Reform of Marijuana Law	bowel accidents on a trip... try and figure out what caused it and you make a note of it, chalk it up to experience ...mom taught him to be advocate. Mother helpful--good advocate.. steps in when he needs help. Moods contagious fake it till you make it	. Sees self has having fewer paths.... just kind of exist one day at a time. And if that means that every other morning I have to get up and have someone put fingers in my butt then that means I have to get up every other morning and have someone put fingers in my butt.	Just shy of so-so.still live in first worldrare bouts of intimacy with wife nice. my bowel regimen isn't even that bad because it gives me a good block of reading time....grocery shop once weekly Sometimes gets bored.
VA-033 69/27 R=2 QOL=7	Highly supportive wife and strong military background. Injured when falling out of a tree while hunting.	life started a whole new because I had to learn to do everything for myself. I drive. I get really frustrated and irritated if something, the least little thing, I get frustrated because I can't do it... Well the way I care about myself and I believe in Jesus Christ, and	I want to feel as much of a man as I can..I'm adjusted to this. I've accepted the condition I'm in because it could be a lot worse, I've seen some guys that can't feed themselves. get up in the morn ng thinking well what am I going to do today? I I	get up in the morning thinking well what am I going to do today? I do this, I do that, I try not to think about the situation, about being paralyzed in a wheelchair... I feel like because it's not just so-so, so I picked the one right after.

		positive people around me that are helping me	feel like my life is still complete to a degree.	
UM-005 35/19 RS=2 QOL=7.5	Teacher,fulltime career, hobbies are writing, exercise; health focused. a 7 because it's not just so-so,	I have to catheterize 2-3 times daily. I rather not catheterize but I can't get all the urine out. I wear a pad and had accidents (leakage... more at night when I have... would rather be married because I'd have some help. The loss of B&B function does not impact my ability to have professional... always been able to have jobs	Just went to Las Vegas all by myself.do not feel that it (disability) limits me if I want to do something.... having SCI as a whole causes the insecurity for any-one... You don't feel as pretty...as able, But I've overcome those emotion	Like how independent I am feels great, but sometimes I do wish I did have more help..if I were walking the way that I want to be walking now, like with a cane or nothing, I would have probably told you like a nine. happy I can walk with crutches but I'm still not fulfilled ... taking me a while to get functional with one cane.
UM-008 63/22 RS=2 7.5	Worked 21 years after her injury; co-work- rs very supportive. Currently retired. Owns a farm Has some bowel sensation	Does bowel and bladder care I think work adds meaning to your life or at least most work does I think. My work did. It adds meaning to your life and gives you a purpose. Y her own.	I just found it that part of the whole loss of the lower half of my body really distressing..	Well I'm, I was pretty successful in my career. You know financially I'm probably fine. Well I'd love to be to walk again... I'd love to be able to do more physical things ...have my family
VA-006 57/36 RS=2 7.5	Married divorced twice-retired; airforce retired volunteers	Self-conscious; Cleveland good experience; could definitely be a lot worse off, so I started thinking about, you know ok, working with what I had. Involved with a lot of activities;	<i>Regarding bowel and bladder dysfunction</i>] It is a significant change in lifestyle that you have to make allowances for. Now drives a car You know it's an independence thing. You want to be able to prove that you're still able to get along on your own	Because it's certainly not a 10, but it's pretty good. There's things I got to deal with but that's just the hand of cards I'm dealt and I have to make the most of it. a great family and I got a lot of nieces and nephews and plenty of friends example of diaper at a bar
UM-044 27/1 RS=1 7.5	Diabetic ketoacidosis led to stroke tospinal cord Currently on long-term disability Injured less than a year at time of interview and stayed at skilled nursing facility for 7 months. Self -reported as strong-willed	I'm still hoping that I can walk again and I'm you know, I'm very determined. I'm very strong-willed and sometimes stubborn so I'm not going to give up. For some reason God wanted me to go through this being sad is not going to change the outcome	don't ever remember thinking oh, my God, I'm never going to be able to go to the bathroom again, and I don't think it still hasn't hit me. It's just like maybe I'll learn to walk again... But I mean everything just changes. You look at everything differently. Just your outcome on life you know, you start to appreciate things better	.'... Like so it's not the worst but am I doing the best? No, because I mean I could be walk... , but I'm better off than where I was. I try to see the positive in any-thing and I you know, my hands... <i>Least enjoyable</i>] The bladder and bowel and the not walking and doing just simple things I can't do on my own anymore
VA-016 58/28 RS=0 7.5	accident. Suffers from lymphedema that makes his bladder hard to manage... Works as a "dog behavioralist" to train dogs for people.	I've talked to God a lot and I can take anything. And I'm not asking a lot, I'm not asking God to walk, bowels and bladder would be nice. They say this is incurable....involved in several incidents So I've had this body be beat up pretty good. So it's not like I've tended to it very well let's put it	You can't stop me. From the first day I got in the chair after I learned I broke my back... was looking straight up at the sky there's one star with a light that came right down straight at me and got about as high as this room then went boom! And I went oh, ok. I got it. And the next thing I heard was, "Is anybody down there?" And I've been fine	well I don't ever give up. I don't ever surrender. I never give in no matter how bad it feels I wish it could be a 10. The pain is like, 1-10 it's a 12. But again, that's just everything combined into itself so it's just something you have to live with so I can never be so-so. I've never been in the middle.
VA-018 57/36 RS=0 7.5	Was a sergeant in the Army. His sister is his main caregiver. No relationships or friendships other than family. W Says he has no friends. Many internal contradictions in his stories and perspectives.	now it is taking too much time and I have no really outside life due to concerns over accidental bowel movements. So I am putting in to get an elective colostomy done... it's a hassle and it wears on your nerves and sometimes it can be embarrassing. That' You have no control over your own life	<i>Regarding accidents</i>] Yeah I've had accidents ...but only a couple times/ But my life is good. I have a good life. I own my own home. I have a van paid off. A home almost paid off times since I've been hurt but only a couple times..	I do anything I want to do. I don't think I really know that much joy except for when my daughter was born and when me and my dad used to hang out. [<i>Least enjoyable</i>] Just being stuck in this damn chair is one of the least enjoyable things. It's just something you have. My life is not great, but my life is not terrible

Response Shift and Perceptions of Quality of Life (QOL) in Newly versus Long-term-Injured Persons with Spinal Cord Injury (SCI)

1. Introduction/Background:

Defining QOL after disability has implications for long-term adaptation and treatment readiness. The concept is highly subjective varying for same person over the life trajectory. “Response shift” captures individual changes over time, as influenced by patterns of coping, reframing expectations, and meaning-making. Understanding patients’ changing perceptions of their own QOL is important for clinicians in assessing and implementing treatment plans and assisting patients in coping with their injury long-term.

2. Materials and Methods:

A mixed method approach was used to study perceptions. Using qualitative interviews, data were collected on the impact of neurogenic bowel and bladder on quality of life for veterans and non-veterans with SCI. Participants also completed a series of questionnaires within two weeks of their interview (BBTI, PROMIS, SCI-QOL) to assess bladder and bowel management, complications and QOL. Data was analyzed using NVivo software, Chi-square and ANOVA. Participants (n=29) were recruited from registries at a large medical center and the local VA clinic.

3. Results:

The average time since injury was 21.3 years with 9 participants with injuries of less than a year. Conceptualizations of “physical independence” emerged as a salient theme across participants. Comparing group responses revealed significant conceptual and meaning-driven differences in the nature and place of independence in participants’ QOL. Newly injured participants characterized loss of independence as a negative influence on their QOL. Those injured more than ten years described independence as something once challenged and now regained, having an overall positive influence on their QOL. References of bladder and bowel effects on QOL were presented among 45% of those newly injured. Differences were noted with respect to QOL ratings ($p<.04$) and with social role activities ($p<.001$). There were no differences between military and civilian participants.

4. Conclusions:

Notions of “independence” appear to change over time, reflecting a response shift as those living longer with SCI learn to adapt and redefine their independence as it relates to QOL. Recognizing these patterns can assist clinicians by signaling patient readiness to treatment that can best improve QOL.

RESEARCH PAPER

Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel

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Abstract

Purpose: Neurogenic bladder and bowel (NBB) is a chronic condition hindering the functioning and quality of life (QOL) of people with spinal cord injury (SCI). NBB research has focused on men with SCI leaving unanswered questions about women's experiences of living with NBB. The purpose of this study was to identify and describe women's experiences of living with SCI and NBB. **Method:** Secondary analysis of semi-structured interviews from a larger qualitative study of women with SCI ($N=50$) was carried out. Transcripts were coded for bowel and bladder content. Pile-sorting techniques were used to identify emergent themes related to NBB. Meta-themes were categorized under the International Classification of Functioning, Disability and Health. **Results:** Bladder and bowel topics were spontaneously discussed by 46 out of 50 study participants suggesting the salience of this issue for women with SCI. We identified 6 meta-themes: life controlled by bladder and bowel, bladder and bowel accidents, women's specific challenges, life course disruption, bladder and bowel medical management, and finding independence. **Conclusions:** Findings describe concerns, strategies, and the detrimental impact of NBB in the lives of women with SCI. Findings inform policy makers, health care and rehabilitation professionals to improve accessibility and quality of life for women with NBB.

Keywords

Bladder, bowel, qualitative research, spinal cord injury, women

History

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► Implications for Rehabilitation

- Women with spinal cord injury (SCI) reported gender specific challenges to living with neurogenic bladder and bowel (NBB). Interventions designed for women with SCI can address these problems and provide recommendations for prevention and treatment.
- Women described the detrimental impact of NBB on life course expectations, emotional, social, physical health, and quality of life domains. Psychosocial and educational programs can be developed to address these challenges and improve overall quality of life.
- Recommendations for special treatment and policy considerations are needed to maximize women's independence and health while living with NBB after SCI.

Introduction

Neurogenic bladder and bowel (NBB), is one of the most stigmatizing and life-changing consequences of sustaining a spinal cord injury (SCI) [1–3]. Problems with NBB are associated with worse physical functioning, pain [4], mental health, social and emotional functioning [5], sexual functioning and satisfaction [6,7], and greater utilization of therapy services [4]. One community-based study indicated that over 40% of adults with SCI rate NBB as a moderate to severe life problem [8]. In fact, in terms of health-related priorities, people with SCI rate improving bladder and bowel function as important or more important than

improving motor functioning [3,9,10]. Furthermore, successful NBB management is associated with improvements in quality of life (QOL), health and (re)integration into social life post SCI [1–3].

Although NBB has been identified as a significant factor in the QOL for people with SCI, our full understanding of the experience and management of NBB is limited by methodological weaknesses in the current literature. With a few exceptions, the current research has relied on quantitative measures of narrowly defined domains (e.g. symptoms, functioning) to examine the impact of NBB on QOL. This approach is not optimal as there are few SCI-specific measures that are designed to adequately measure QOL [11], let alone the specific impact of NBB on QOL. This limits our ability to assess the potentially broad range of QOL domains relevant to those with NBB secondary to SCI. Furthermore, in this approach, the researcher, not the consumer, decides which domains are important to examine. Consequently, crucial information related to the experience and management of

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Table 1. Sample questions from a 13-question interview guide.

1. I would like to begin this interview by asking you to tell me a little bit about yourself –anything you might wish to share that will help me to get to know you better.
2. Can you tell me about your spinal cord injury experience and what you remember about the challenges you faced during the early weeks and months after your injury?
3. Over the years, how did you come to make sense of your injury and your life after your injury?
4. With respect to your daily life, right now, what are the challenges that cause you a fair amount or a lot of stress these days?
5. In your own words, how would describe the overall quality of your life. When you look back to the time when you first became disabled or when you first learned of your disability and its consequences, what went through your head?
6. How has living with a spinal cord injury shaped your “sense” of yourself as a person?
7. Are there any other things that you care to share that you think are really important for us to know about when we talk to other women like yourself?

NBB may not even be assessed. Ultimately, the extant quantitative research does not provide adequate insight about the perspectives of people who are living with NBB after SCI.

Qualitative methodology is best suited for learning about the experiences and the perspectives of people living with SCI [12–16] and can be used to provide a more comprehensive understanding of living with and managing NBB [11,17]. The existing body of qualitative research has focused narrowly on specific types of NBB treatments (i.e. functional electrical stimulation) [2], self-management strategies (i.e. intermittent catheterization) [18,19], or the impact of NBB on sexual functioning [6,20]. Additionally, both quantitative and qualitative research has primarily focused on men because they represent the majority of SCI cases [21]. However, there is a critical need to understand the experiences of women with SCI and how physiology, cultural barriers, management strategies, and sources of stigma may influence experiences of women living with NBB [21]. Preliminary survey research suggests that women have unique concerns and challenges related to managing NBB, such as difficulty with self-catheterization due to positioning, accidents during sexual intercourse, and reliance on formal caregivers rather than assistance from romantic partners [7,9,11,22]. Although, the current literature suggests that women may have concerns that are distinct from men, research to date has not used qualitative methods to develop a more complete understanding of women’s experiences living with NBB after SCI.

To address these gaps in our knowledge, the purpose of this study is to identify and describe the experiences of women living with and managing NBB after SCI. The central research question is: How do women with SCI describe the impact of experiencing and managing NBB on their QOL? The scope of this question is intentionally broad, as the full extent of the impact of NBB in the lives of women with SCI has not been previously characterized. By providing a detailed consumer’s view of life for women with SCI and NBB, findings from this study may also offer key insights about the full impact of NBB, barriers to adherence, and factors that contribute to primary and secondary health complications. A secondary question was: How do the ways that women describe the impact of NBB on their QOL map onto the International Classification of Functioning, Disability and Health (ICF)? The goal of mapping the salient themes from the analyses onto the ICF is to provide a concrete framework to inform health care policy, clinical research, and practice. Illustrative quotes from the women in the study provide a rich, salient, and poignant depiction of the personal and detrimental impact that NBB has on their lives.

Methods

Study design

This is a secondary data analysis of in-depth and semi-structured interviews collected during a 3-year study focusing on stress and coping over the life course among women with SCI [21,23–25]. Fifty community-dwelling women with a SCI were recruited from

two rehabilitation facilities, the University of Michigan, Ann Arbor, MI, and the Rehabilitation Institute of Michigan, Detroit, MI. The Institutional Review Boards of the respective facilities approved this study. Each participant provided informed consent and completed one in-depth face-to-face or telephonic interview. Interviews were semi-structured and questions were focused on stress, challenges, and difficulties of living with a SCI as well as coping, resilience, and adjustment to SCI (Table 1, for example questions). Interviewers were trained research staff and women, who had a visible physical disability (polio or SCI). Interviews were audio-recorded and lasted approximately 1.5–2.25 hours (mean = 1.75). Interviews were transcribed verbatim by a professional transcription service.

Sample

The goal of sampling was to select women, whose experiences represented not only variation across race/ethnic groups, but also across the lifespan and with respect to the number of years lived with SCI. See Table 2 for key sample descriptive statistics.

Data analysis

Content coding and thematic analysis were conducted to understand the experiences of women living with and managing NBB [26–28]. Interview transcripts were imported into QSR International’s NVivo 10 software [29]. The first author (AN) reviewed several transcripts to identify keywords related to bladder and bowel discussions. Using the search and auto-code function of the NVivo software, 26 keywords were used to identify and auto-code bladder and bowel related content (e.g. bladder, bowel, cath, bathroom, colostomy). The transcripts were read (AN) to identify and hand-code subtle references to bladder and bowel such as “my bodily functions were under the control of someone else” that were missed during the auto-coding step.

References to bladder and bowel were then extracted from NVivo and two Ph.D.-level investigators with qualitative expertise (AN, AK) utilized pile sorting techniques to identify emergent themes and topic categories that characterized the data [30]. Pile sorting is a well-established qualitative technique where data are printed on paper and then sorted into various piles based on common themes or topics [28]. The investigators completed five pile sorting sessions, each lasting approximately two hours. An iterative process was used to review each text reference and sort related references into piles. The investigators discussed each distinct NBB quote until they reached consensus about the best-fitting pile/theme. If an existing pile/theme did not seem to suit the content of the quote, the investigators would create a new pile and discuss the name and definition for the new theme until they reached consensus. During the sorting process, the investigators maintained a list of themes so they could easily see which themes were available. Process notes, or “memos” were also kept for the documentation of the decision making process during the pile sorting phase and the emerging thoughts about how groups of

Table 2. Women with spinal cord injury demographic information.

Demographics (N = 50)	Mean (SD) Frequency (%)
Age (in years at time of study)	
M (SD)	45.6 (14.9)
Range	22–85
Ethnicity/race	
White	26 (52%)
Black	24 (48%)
Method of injury	
Motor vehicle accident	24 (48%)
Sporting injury	2 (4%)
Violence	13 (26%)
Fall	8 (16%)
Other	3 (6%)
Level of injury	
Paraplegia – incomplete	11 (22%)
Paraplegia – complete	10 (20%)
Tetraplegia – incomplete	16 (32%)
Tetraplegia – complete	13 (26%)
Time since injury (years)	11.3 (9.8)
Marital Status	
Married	13 (26%)
Single	17 (34%)
Divorced	15 (30%)
Widowed	5 (10%)
Education	
Less than high school	1 (2%)
High school diploma or GED	29 (58%)
Associates/Junior College Degree	6 (12%)
Bachelor's Degree	7 (14%)
Master's Degree	5 (10%)
Missing	2 (4%)
Employment	
Currently working for pay	9 (18%)
Employed prior to injury	43 (86%)
Employed after injury	21 (42%)
Family	
Have children	35 (70%)
Had children after injury	6 (12%)
Live alone	11 (22%)

similar themes (“sub-themes”) seemed to fall under broader themes, or “meta-themes” of QOL related to NBB.

After all paper slips were sorted into piles, the sorting results were entered into NVivo, “nodes” – NVivo language for a “code” were created for each meta-theme, and all references were coded according to their pile sort theme. The investigators reviewed quotes in NVivo and their process notes together to confirm the themes developed through pile sorting process, which related to the research question. Exemplar quotations for each meta-theme were identified by the investigators and were used to illustrate each theme.

Lastly, the authors applied the meta-themes to the International Classification of Functioning, Disability, and Health (ICF) model [31]. The ICF is a biopsychosocial model that is used to integrate medical and social models for a holistic understanding of disease, illness, and disability [31]. The investigators examined the meta-themes in the context of the ICF to draw conclusions about the role that NBB has in the health and functioning of women with SCI and extrapolate implications for patients, clinicians, policy makers, and researchers.

Results

Based on the data analyzed, 69 subthemes were categorized under six meta-themes, which reflected the women's reported experiences of living with and managing neurogenic bladder and bowel

(1) life controlled by bladder and bowel, (2) bladder and bowel accidents, (3) women's specific challenges, (4) life course disruption, (5) bladder and bowel medical management, and (6) finding independence. Figure 1 illustrates how the themes were mapped onto the ICF model.

Meta-themes

Life controlled by bladder and bowel

This was the central meta-theme in women's discussions about life after spinal cord injury that generally reflected the life-altering impact of NBB. Participants' statements epitomized the all-encompassing and negative consequences of NBB, and the women described how the incredible amount of time, planning, preparation, and unpredictability of managing NBB hindered daily activities, responsibilities, and social relationships.

It's really hard to have your life controlled by your bladder and bowel function. (age 42, white, 7 years tetraplegia-incomplete)

My cathing situation is the biggest stressor in my life now. (age 54, white, 1 year paraplegia-complete)

I have a schedule because a lot of things revolve around my bathroom. Between drinking and bathroom, between bowel and bladder. I need to know in advance what I'm going to do. If I'm going to be a participant in this program, whether someone's going to come and visit here. Just like people will have to be concerned about cleaning their apartment when people come to their house, rather, you know, I have to think of that as well as my bladder and bowel issues. (age 26, African American, 6 years tetraplegia-incomplete)

Women described how frequent bladder care and difficulty finding accessible bathrooms was a major problem and barrier to participate in social activities outside of the home. Some women reported choosing to stay home rather than go out to avoid challenges to bladder and bowel care. When away from the home, women described restricting fluid intake to reduce the need for urination and/or were unable to perform bladder care, which endangers bladder/kidney health and may lead to autonomic dysreflexia.

In outings with the kids, I want to go with them but I just rather stay at home because it will be awkward and cumbersome trying to go. My legs start hurting and burning or I have to use the bathroom every two hours. It's bothersome. (age 43, African American, 4 years paraplegia-incomplete)

I went to a hockey game and they have no accessible bathroom. You have to get there early for parking and the games are two or three hours long, the last thing you want to do is have to sit and stress during a game over. I can't make it three or four hours. Or Don't drink anything because there's no accessible bathroom. (age 33, white, 17 years paraplegia-complete)

Women explained that the unpredictability and time commitment related to their bowel management program was particularly disruptive to their ability to participate fully in life.

It's a waiting game until it (bowel training) starts. Sometimes she (attendant) might be here three hours, and other times she might be here 20 minutes, that's more stress than anything. I do not schedule anything for Friday and

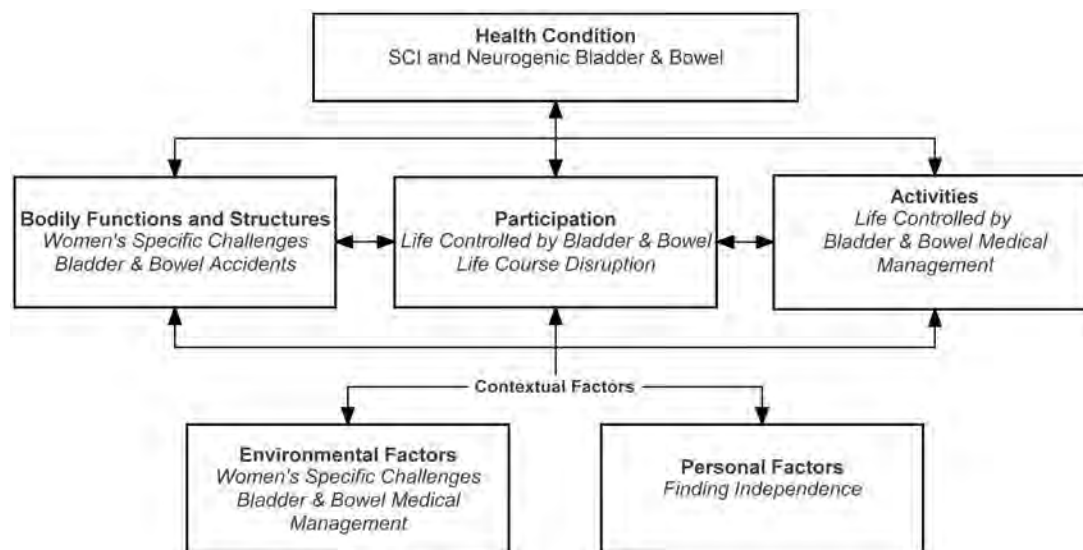


Figure 1. Neurogenic bladder and bowel meta-themes (*italics*) mapped onto the International Classification of Functioning, Disability and Health (ICF).

Monday afternoon. I have most of my friends trained not to come visit me on Monday and Friday afternoons. (age 65, white, 8 years paraplegia-complete)

It's tedious to go through bowel training, but that's what you have to do so that you don't end up sitting in feces all day. (age 32, African American, 13 years tetraplegia-incomplete)

A real big problem with my spinal cord injury was constipation. You can't go a lot of places because you have to take care of that problem, and so they think, "Well, bam! We'll come over and get you and we're going out to eat," and I go, "Oh, just a minute, I can't go that quickly" because maybe I'm sitting around waiting to use the bathroom. It's something that's difficult to talk about. (age 66, white, 3 years tetraplegia-incomplete)

It was evident from women's discussions that the NBB management programs were a burden, source of stress and suffering in daily life, and barrier to engaging in desired life activities. Themes referred to the unpredictability of their conditions and the need for preparations to anticipate problems with methods of management, the lack of accessible physical environments, and complications.

Bladder and bowel accidents

This was a meta-theme that reflected the uncontrollability of the women's bladder and bowels and the experience and impact of bladder and bowel accidents. Many women reported worrying about the potential for accidents, particularly when in public, and the humiliating experience of a bladder or bowel accident. The potential for accidents was cited as a major reason some women would not leave the home and the women described anxiety and worry about accidents when they ventured out of the home.

My bowels, have a mind of their own, no matter what I try to do. I get to the point sometimes that I'm afraid to go anywhere and do anything because my bowels are going to work up and that embarrasses me. I don't want to be embarrassed, or embarrass my husband or mess up my car or his car, or stuff like that. Having to worry about that all the time just gets me, it wears on me. (age 47, white, 18 years paraplegia-incomplete)

If I'm out in public, I'm really embarrassed because I'm worried if someone can smell the urine and what type of image that's projecting to people around me. Are they going to assume that people in wheelchairs are nasty or unkempt? (age 32, African American, 13 tetraplegia-incomplete)

Many women described feeling dependent, vulnerable, embarrassed, and frustrated when relying on others to clean up after accidents.

One Christmas I had an accident at Jim's mom's house and Jim had to change me. I couldn't get in any of the rooms. So he's changing me in the dining room in my wheelchair. His brother-in-law – is holding one leg up. His father was on the other side of me. And my sister-in-law was here. I made the best of it. I said, "Look here, I got two men and two women," or something. Incredible. But I did it twice there. [bowel accident] I had to change it twice. And that was aggravating, frustrating. (age 40, white, 8 years tetraplegia-complete)

Not being able to control the things in my body, like bowel movements. And so I call them incidents instead of accidents because it wasn't necessarily an accident because I couldn't control it. Having that happen while out in public and having to leave and people noticing that I wet myself or had a bowel movement while I was out in public. Then I would have to go back and have somebody clean me up because I couldn't do it myself. That was one of the worst things. I remember one time that I had a bowel movement and peed on myself and I had to have a girl put me back in bed and clean me up. It upset me so much. I couldn't do that kind of stuff for myself. (age 40, white, 4 years paraplegia-incomplete)

Some women talked about taking steps to prevent or mitigate the impact (e.g. wearing incontinence pads) of accidents.

I watch what I eat because it will give me diarrhea. That's an embarrassing thing. If we're going out or something or out of town, I wear like panty shields or a pad or something like that, just in case. It doesn't happen all the time but I have had it happen and that's a big issue for me. (age 61, African American, 17 years paraplegia-incomplete)

Women's specific challenges

This was a meta-theme that primarily captured problems with catheterization, regardless of whether the women catheterized independently or relied on assistance from others (e.g. caregiver, attendant). Women emphasized that because of their anatomy, they needed to recline or lie flat and remove their clothing in order to access the urethra for catheterization. Women also noted how limitations in hand, arm, and leg dexterity and strength made removing clothing especially difficult and interfered with the catheterizing process.

Doing the bladder and intermittent self-cath was really hard because us being women and the way our anatomy is set up. I would have to recline in the chair. I had snaps in my pants, I didn't wear underwear, so that the nurses could have access to do the cath every three to four hours. (age 42, white, 7 years tetraplegia-incomplete)

My cathing situation. According to the urology nurse, I should be able to transfer myself over onto the bed, get my pants down and cath myself. I'm not able to do that—not able to get in and out of my chair without help and not able to undress my lower half by myself. I can cath myself and I have done it many times, but only after help getting on the bed. (age 54, white, 1 year paraplegia-complete)

Despite the Americans with Disabilities Act (ADA) architectural specifications, numerous women reported challenges in finding accessible bathrooms that were large enough for them to recline/lie down. For some women, this meant they were unable to take care of bladder needs outside of their home.

Whenever I went out anywhere, I was always in search of a restroom that was large enough to allow me to lean back in my chair. It was tough. (age 42, white, 7 years tetraplegia-incomplete)

The whole bathroom situation, makes me less likely to jump into any kind of situation because I'm afraid there will be a problem with the whole bathroom situation. (age 25, white, 9 years tetraplegia-complete)

I go out and then I'm like, "Oh, I need to get home because I have to pee." (age 27, white, 3 years paraplegia-incomplete)

Women frequently mentioned how catheterizing in an automobile, specifically a van, was an alternative option when having difficulty finding accessible bathrooms. Access to an automobile is an important consideration for women in need of a space to catheterize and manage their bladder when they are away from home.

I can do it (cath) in the back of my van, prop my legs up on the seat and do the intermittent cath. So that's good. (age 54, white, 36 years tetraplegia-complete)

Another women's specific challenge was increased bladder incontinence during menstruation. One participant described increased bed wetting around her "period time" and was unsure if her personal attendant was catheterizing her properly during or if the increased incontinence was related to menstruation (age 51, white, 8 years tetraplegia-complete). Similarly, another participant recounted an incident where she told her nurse about increased self-care challenges from menstruation and bladder incontinence.

The nurse says, "Where's that blood coming from?" I said, "I am so sorry." I said, "I'm having my period." She said, "Do you usually bleed that much?" And I said, "Well, it's mixed with urine." And she said, "What do you mean, it's mixed with urine?" So I told her what was happening. (age 49, African American, 9 years paraplegia-incomplete)

In many cases, women felt unprepared to address their needs and specific problems associated with methods to empty their bladders.

Life course disruption

This was a meta-theme that reflected how NBB restricted women's ability to meet or fulfill social and cultural norms, expectations, roles, and developmental stages. People often experience suffering and turmoil when they realize they can no longer fulfill important life course expectations [32]. Women from this study specifically highlighted independence, career, and social/sexual relationships as important yet disrupted life course expectations. Women described an abrupt loss of independence after a SCI, because they were no longer able to manage their bladder and bowel. Women explained how loss of bladder and bowel control made them feel "off time" because they were unable to meet this important adult life course expectation.

A sudden loss of complete independence. I had to be fed. I had to be catheterized, I had to have my bowel movements monitored and enemas and had to have my rear end wiped. All of my bodily functions were under the control of someone else...I have become dependent which is shocking everyone. All my friends go, "This isn't the Mary we know!" I was stronger than a lot of men. I prided myself on being strong and tough. I've done a lot of jobs that were male-dominated. People look at me and "Wow! You're just not the same Mary! You're dependent on people. You're not as aggressive. You're not as assertive." It's like, "It's called paralysis!" I almost want to get angry. You don't know what it's like to be in this body! (*emphatically*) (age 52, white, 2 years tetraplegia-incomplete)

Like a baby, completely dependent on somebody to change your diaper. When a woman finds herself wearing diapers, it's a very difficult thing. (age 66, white, 3 years, tetraplegia-incomplete)

I'm embarrassed at my age to be wetting myself, even though it's not my fault. I still feel embarrassed that I'm this old and unable to control something like that. (age 32, African American, 13 years tetraplegia-incomplete)

Having to regress to a stage of physical dependency on others for basic needs was expressed as a major issue in adjusting to losses associated with a SCI. It is well reflected by the above statements, that women also experienced feelings of shame, loss of self-respect and dignity, and low self-esteem.

Women discussed how managing NBB constrained career opportunities and social interactions. Participants expressed anxiety and concerns about being able to properly manage bladder and bowel and access bathrooms outside of the home, which resulted in decreased social interactions and career opportunities. Many women were reluctant to leave their homes to work because of concerns about accessible bathrooms.

I'm generally kind of discouraged because I don't have a job and I don't have a family. I can't go back to work at the moment because I can't control my bowels. We have not

been able to regulate it so I can't get a job, especially if I can't even go to the bathroom while I'm there. I just don't have the motivation to do a whole lot right now. (age 40, white, 4 years paraplegia-incomplete)

Participants highlighted how living with neurogenic bladder and bowel negatively affected relationships with family members and romantic partners, including disrupted parental roles and problems with intimacy and shame with new and long-term sexual partners.

When I did my bowel programs with the nurse I was thinking, "My daughters are seeing this" and they know what's going on. Talk about vulnerable! It was difficult for them and difficult for me and I thought, I will never be able to parent. I will never be able to do that again. (age 53, white, 11 years paraplegia-complete)

My husband did not want to be reminded of the injury. He didn't want to see a glove in the wastepaper can in the bathroom. His way of dealing with it was to ignore as much of it as he could. So I was very secretive. I would not use the word "cath." That word was not to be spoken. If we were in the bathroom and I was draining my leg bag, I didn't want the sound of the water entering into the toilet. There were a lot of changes, but it was more for his sake than my own. (age 42, white, 7 years tetraplegia-incomplete)

A part that's kind of hard to talk about a spinal cord injury can really affect a marriage, especially with a woman – is her husband willing to take care of her? My husband had to take my diaper off and put it on. Women need to see how this can affect your marriage. Hopefully you have a spouse that will take care of you. (age 66, white, 3 years tetraplegia-incomplete)

I still have problems with my bladder. I can't control my bladder or my bowels. "What if we go out on a date and I need to use the bathroom?" Or when it came time to be intimate with a guy, "What if I have an accident?" I've never done this before, I didn't know how to talk to a guy about it. (age 25, African American, 22 years tetraplegia-complete)

The examples discussed above underscore the damaging impact of NBB on life course expectations, primarily in the area of independence, career, and social/sexual roles and relationships. They also reflect how NBB affects participation in societal activities as defined by the ICF framework.

Bladder and bowel medical management

Women discussed how some medical management options (bladder diversion surgery, indwelling catheters, Foley catheters, leg bags, and colostomies) served to reduce the burden of bladder and bowel programs and caregiver dependency by improving independence, freedom, and quality of life. Women described a dilemma between "gold standard" bladder programs (e.g. self-intermittent catheterizing) that are burdensome and limit independence versus medical management programs that are considered medically risky (e.g. indwelling catheters) but are less burdensome and improve quality of life and independence.

After a year, I went to [the doctor] and they gave me the option of keeping an indwelling catheter in. And that freed my life up so much! I understand the issues, you know, it's a balancing act as to what's better and what's not. I could not

go back to intermittent cath, I could not do it. I couldn't have my life again controlled by that. (age 42, white, 7 years tetraplegia-incomplete)

I have a colostomy. It first frustrated me because I didn't like having a hole in my stomach. But in the long run, it's so much easier than a bowel program. I appreciate it. The bowel program would take four hours. It sometimes can go for days and it would hurt. With this [colostomy], I have no problem now, I don't have the accidents. (age 40, white, 8 years tetraplegia-complete)

What I do is, I wear a leg bag, an indwelling catheter and a leg bag when I travel on a plane or when I snow ski. (age 54, white, 36 years tetraplegia-complete)

Women also highlighted barriers to certain medical management programs for NBB. For example, some women reported having inadequate input about how their NBB was medically managed and how certain management programs were not covered by insurance.

The main stressor in my life right now is cathing, trying to find a different way to handle this. I want to go with an indwelling Foley but was told by the nurse today that's not a good way to go because it could be damaging to your urethra and could cause cancer, which I didn't know...My husband had surgery and he was not supposed to lift anything heavy, so I did have a Foley for a while and it made my life so great. By myself, in my car, I wouldn't have to worry about trying to be somewhere and have someone help me cath—it's a very independent feeling, but I feel now the doctor wants to take that away from me now because that time is over with. (age 54, white, 1 year paraplegia-complete)

I'm paying caregivers out of my pocket which can be very expensive at times. I got to find a job so I can have money. I want to have this surgery to make me more independent. I don't know what you call it, to do the cath in the bellybutton. But I'm hoping that will make me more independent. I will be able to eliminate a couple caregivers, maybe, and I'm looking forward to that. (age 44, African American, 14 years tetraplegia-complete)

These methods of management also imply loss of independence, thus affecting their overall quality of life.

Finding independence

This is a meta-theme, that includes women's explanations of the importance of redefining and finding independence despite facing a wide range of barriers, challenges, and limitations associated with living with and managing NBB. Discussions about finding independence with SCI were often contingent on mastering the task of self-intermittent catheterization for bladder care.

Until I could cath by myself, I couldn't be totally independent. (age 53, white, 11 years paraplegia-complete)

I think I regained my independence when I was able to go to the bathroom by myself. (age 53, white, 36 years tetraplegia-incomplete)

A big turning point was when I was able to finally cath out of my chair by myself. As much as I pee my pants I want to just be able to take care of myself. (age 27, white, 3 years paraplegia-incomplete)

Women described changing how independence was defined prior to SCI and finding creative ways for establishing independence post SCI. Examples of resilient philosophies used to find and redefine independence include:

Within the levels of my disability, I have to find independence in there. I have to prove my own independence. I have to tell my caregivers "I can do this" because sometimes they just want to be right there and do it all for you. If I can start to successfully self-cath on a consistent level, that's going to pull me up a lot. If I can self-cath and I don't have to have someone there to cath me every four hours it's going to free me up a lot. I can just go in the bathroom, do it myself. (age 52, white, 2 years tetraplegia-incomplete).

I look at myself as totally independent now. Independent in the sense of no one has to bathe me or dress me or cath me. (age 41, African American, 5 years paraplegia-incomplete)

Reducing family caregiving burden by learning how to self-catheterize was a major motivation for finding independence.

My daughter was such a special gift from God. Even though she was six, she used to say to me—because I was still learning how to cath myself—"Mama, I'll help you with your catheterization" or "Mama, let me get your foot while you do that." I guess all the more reasons why I really wanted to learn to be as independent as possible because I didn't think that she should have to just wait on me all the time and help me do those kinds of things. (age 53, African American, 28 years tetraplegia-complete)

These women's accounts highlight self-catheterizing as a crucial component for establishing independence after SCI.

Mapping themes onto ICF model

As seen in Figure 1, each of the ICF domains is related to the NBB themes identified in this study. The ICF participation domain was primarily reflected in the content of two themes, "life controlled by bowel and bladder" and "life course disruption". These themes capture how NBB interferes with full and normative participation in social/emotional, vocational, and physical activities, both inside and out of the home. The "life controlled by bladder and bowel" theme also fit within the ICF Activities domain, as it described how activities of daily living were difficult and almost untenable in some cases. Due to the burden of the bladder and bowel program, the demands of this activity of daily life had tremendous impact on all aspects of the Participation domain. The ICF Bodily Function and Structures domain was reflected in the themes of "women's specific challenges" and "bladder and bowel accidents" together, these themes capture how the female anatomy and the physiology of NBB create unique challenges to carrying out the bladder and bowel management program (Activities) and present barriers to full Participation in broader life activities. Evaluation of Environmental Factors, allowing for the identification and remediation of barriers to activities of daily living and participation, is one of the major strengths of the ICF [31]. The themes that best reflected the ICF Environmental Factors domain were "women's specific challenges", which highlighted the inadequacies of accessible restrooms for women, and "bladder and bowel medical management", which highlighted that women may not have access to the medical management programs they want or need due to lack of influence in the medical decision making process or lack of insurance coverage for a given device/procedure. Like the other ICF domains, Environmental Factors is strongly related to

Participation and Activities. Finally, the "finding independence" theme was conceptualized as a highly-individual factor related to aspects such as coping style and personality. As such, it was mapped onto the ICF Personal Factors domain and seemed to be a strong influence on the Participation ICF domain.

Discussion

The women in this study described NBB as a major source of stress and frustration in their daily lives. Our findings provide insight on a range of concerns, experiences, expectations, and problem solving strategies of women who are living with the loss of bladder and bowel function after SCI. These findings may inform health care professionals programs, rehabilitation, insurers, and public policies to improve accessibility and quality of life for women living with spinal cord injury.

The findings from this study highlight the sociocultural impact of NBB on women's experiences of living with SCI. We learned that even after living with SCI for an average of 11 years, women's lives were still controlled and disrupted by burdensome NBB management programs. Our findings are consistent with life course disruption literature [32], because women had difficulty fulfilling social and cultural norms (independence, career, family) after spinal cord injury. In spite of various daily challenges and difficulty meeting life course expectations, some women described the importance of "finding independence" while living with the constraints of NBB and SCI. Our findings support existing research on women living with SCI regarding difficulty with self-catheterization [18,19], sexuality challenges [6,7], desire to improve NBB routines to maximize independence [8], and concerns about male significant others assisting with NBB care [22]. The six emergent meta-themes from our study expand this literature by providing an in-depth understanding of how women make sense of living with NBB and women's specific challenges towards NBB care (e.g. burdensome self-catheterization, menstruation, reclining/laying, inaccessible bathrooms).

Discussions from the women with SCI on experiences of living with NBB highlight that there is often a dilemma between physical health and quality of life. Clinicians tend to focus on maximizing physical health through bladder and bowel regimens, and typically opt for programs associated with the lowest risk of complication. While these regimens may maximize long-term physical health, they are time intensive, result in caregiver dependence, reduce the individual's independence, and limit participation in important life activities. Findings from this sample of women with SCI reveal a crucial need for more person-centered approaches to maximize independence and quality of life while managing bladder and bowel. Women emphasized a need for increased freedom, maximizing independent self-care, and quicker/easier bladder and bowel programs to allow for greater community integration, participation, and independence.

This study placed the experiences of women with SCI and NBB in the context of the ICF in order to examine inter-relationships between the various themes, identify ways that NBB affected functioning and participation, highlight factors in need of remedy, and relate findings to a broader clinical audience. The ICF context served to reveal the fact that bodily function and structure as well as environmental factors present unique challenges to women that men with SCI and NBB do not face. The ICF also highlights the serious detrimental impact of NBB on participation as well as the importance of an individual's resilience in finding independence when confronted with NBB-related challenges.

Study strengths and limitations

The diversity of the sample in terms of race/ethnicity, age, time since injury, and level of injury is a prominent strength of this

study. We took steps to ensure that our analytic process and findings are reliable and valid. Firstly, to ensure *credibility* (analogous to internal validity), the parent study recruited a diverse sample to increase the likelihood that a wide range of experiences were represented. Credibility is supported, if the accounts seem logical, or “ring true” to the reader. Further, to increase *transferability* (analogous to external validity), the parent study recruited a diverse sample, and we critically evaluated our ability to generalize findings to a broader population. Transferability was supported as our findings were consistent with the current literature. To enhance the *dependability* of our study (analogous to reliability), our data analysis included *researcher triangulation*, where multiple researchers analyzed the data [33–36]. By clearly describing the study procedures, we established *confirmability* (analogous to external reliability).

This study has several limitations. The original study was focused on stress and coping after SCI and not specifically on neurogenic bladder and bowel. The original dataset provided rich information on neurogenic bladder and bowel; however, we were unable to develop interview questions or ask for clarification to responses related to our topic of interest. Our study findings provide in-depth data on women with SCI; however, our study findings are not necessarily generalizable to men with SCI.

Recommendations and future directions

These insights on women’s experiences prompt important questions, such as: *are policy, clinical practice, and medical guidelines meeting the needs of women with neurogenic bladder and bowel after spinal cord injury?* Our findings may inform future research, rehabilitation policy, clinical practice, and resources or management programs to better meet the needs of women living with NBB after SCI. Findings highlight implications for health care coverage and policy in terms of the great need for access to general supplies to address NBB accidents (diapers, pads, cushions), medical supplies and procedures (indwelling catheter, Foley catheters, colostomy, Botox injections), reclining chairs, larger bathrooms, caregiver support for NBB care, vans/vehicles (alternative access to bathrooms), and adaptive clothing. Health care access is a major issue for women with SCI and current health care coverage policies should reflect these needs. Differences between public and private or third party providers should be minimized to address the needs of women with SCI.

Findings also suggest a need for mental health support services for women dealing with distress, stigma, and life course disruption due to NBB. These problems often also result in dysfunctional relationships, lack of social support and personal isolation, and excessive anxiety and depression. Cognitive and behavioral approaches that address these issues may help women solve some of these problems. These are important adjunctive approaches in addition to medical and pharmacological interventions.

Our findings expand on current research suggesting the importance of person-centered NBB management programs [17,37] by indicating the need for women-centered approaches to NBB medical management. Clinicians should discuss the dilemma between medically-preferred management programs and quality of life issues, such as management program burden and loss of independence. It is also recommended that clinicians prioritize women’s perspectives, lived experiences, independence concerns, and needs when making NBB management program decisions. Women patients should be allowed to engage in shared decision making with their clinicians regarding their bladder and bowel program care. Options to use indwelling catheters when leaving the home or other types of temporary or permanent medical management programs to increase independence and reduce the ongoing

burden of self-intermittent catheterization might be considered for some people in some circumstances. Future research needs to more clearly delineate how menstruation may be linked to increased bladder incontinence and/or NBB management difficulties.

Rehabilitation services could focus on ways to maximize independent bladder and bowel self-care through more intensive and ongoing treatment to strengthen the body to improve function, making it easier for women to remove clothing and position their bodies for self-catheterization. Environmental modifications, such as alterations to the ADA architectural specifications are necessary to meet the NBB management needs of women.

The evident tension between medically-preferred (i.e. lower risk) NBB management programs and programs that optimize QOL (i.e. indwelling catheters) indicates a need to improve and develop new technology and management guidelines that are tailored for the female anatomy and women’s specific needs and challenges, particularly for bladder management with intermittent self-catheterization.

Future research is needed to provide additional evidence on women’s health outcomes of specific bladder and bowel programs (short and long-term effects of temporary, intermittent, and permanent use of “non-gold standard” NBB programs; how to reduce frequency of bladder care; decrease duration/unpredictability of bowel care; how women’s self-imposed fluid restriction impacts bladder/kidney health).

Research suggests there are discrepancies between the goals of experts (e.g. health focused) about how to best manage bladder and bowel in comparison to the goals of people with SCI (e.g. quality of life) [38–40]. Non-adherence to bladder and bowel programs can result in serious health problems for people with SCI (e.g. kidney stones, skin sores, urinary tract infections, autonomic dysreflexia) and up until the past few decades, urinary complications were the primary cause of morbidity and mortality in SCI. At the same time, proper adherence to bladder or bowel programs may make it difficult to participate in social activities (e.g. time-consuming, require assistance, inaccessible public bathrooms). Despite recent efforts to improve clinical practice guidelines for bladder and bowel management, additional research is needed to further understand how people, especially women, can participate in desired social activities and intimate relationships while properly managing this condition [41]. Updated clinical practice guidelines and standards for how to best treat and assess these problems in women with SCI are needed.

Conclusions

The purpose of this study was to allow women to identify and describe their experiences of living with and managing NBB after SCI. Our approach highlights how information on the subjective experience is crucial to gain a more comprehensive understanding of the immense impact of NBB among women living with SCI. We encourage future researchers and clinicians to consider the importance of women’s specific experiences, preferences, challenges, and values when deciding how NBB should be managed. Modifications in traditional “gold standard” NBB routines to better reflect women’s needs can have a significant impact the quality of life of women with SCI.

Declaration of interest

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